American University Law Review

Volume 51 | Issue 3 Article 6

2002

Transcript for Panel Three: Privacy: Genetic Profiling and Discrimination

Christopher H. Asplen

F.Samuel Baechtel

Lon A. Berk

Susan D. Carle

Q.Todd Dickinson

Follow this and additional works at: http://digitalcommons.wcl.american.edu/aulr

 Part of the Civil Rights and Discrimination Commons, and the Constitutional Law Commons

Recommended Citation

Asplen, Christopher H. et al. "Panel Three: Privacy: Genetic Profiling and Discrimination: The Human Genome Project, DNA Science and the Law: The American Legal System's Response to Breakthroughs in Genetic Science." American University Law Review 51, no.3 (February 2002): 451-484.

This Conference & Symposia is brought to you for free and open access by the Washington College of Law Journals & Law Reviews at Digital Commons @ American University Washington College of Law. It has been accepted for inclusion in American University Law Review by an authorized administrator of Digital Commons @ American University Washington College of Law. For more information, please contact fbrown@wcl.american.edu.

Transcript for Panel Three: Privacy: Genetic Profiling and Discrimination

Keywords
genetic profiling, discrimination, genetic privacy, genetic discrimination

This conference & symposia is available in American University Law Review: http://digitalcommons.wcl.american.edu/aulr/vol51/iss3/6

THE HUMAN GENOME PROJECT, DNA SCIENCE AND THE LAW: THE AMERICAN LEGAL SYSTEM'S RESPONSE TO BREAKTHROUGHS IN GENETIC SCIENCE

PANEL THREE: PRIVACY: GENETIC PROFILING AND DISCRIMINATION

Washington, DC
Friday, October 19, 2001

MODERATOR:
Jamin Raskin
Washington College of Law

PANELISTS:
LON A. BERK
Shaw Pittman

SUSAN D. CARLE
Washington College of Law

PAUL STEVEN MILLER
Commissioner, EEOC

ELIZABETH BARRY SANDZA
LeBoeuf, Lamb, Greene & MacRae

NANCY SEGAL
Washington College of Law

MICHAEL J. WERNER
Biotechnology Industry Organization

* * * * *

P R O C E E D I N G S

PROFESSOR RASKIN: This is an extraordinarily distinguished and capable panel we've assembled. Each person is going to give you an overview of his or her perspective on the topic of genetic profiling and discrimination. Then I'll ask a few questions and then we will open it up to general discussion. Lon Berk is a partner at Shaw Pittman; Betsy Sandza is a partner at LeBoeuf, Lamb; Michael Werner is the Director of the Federal Government Relations and Bioethics Council at the Biotech Industry Organization; Professor Susan Carle teaches employment law here at WCL; Paul Steven Miller is a Commissioner at the Equal Employment Opportunity Commission; and Nancy Segal is the Legal Director of the Program on Gender, Work and Family.

The first couple of speakers are going to start by focusing on insurance and genetic discrimination and then we're going to phase into the employment law issues.

MR. BERK: Thanks. I want to thank everybody for inviting me to speak here. This is the first time I've been in a law school classroom in sixteen years, and when I was previously in a law school classroom I was always in that back row there, so this is a unique experience for me.

I want to suggest this afternoon that the debate over genetic privacy and genetic discrimination is a misplaced debate and that those concepts should not be employed - that they actually do us a disservice. I will not suggest that there should be genetic profiling or that DNA should be involuntarily taken from people. My concern is with the notion of genetic privacy: the idea that a person has a right to deny access to information about the person's genetic constitution.[1]

1. The notion of privacy with which I am concerned is a notion that applies to information. This should not be confused with a notion of privacy that protects the person's body. In particular, there is a distinction between a notion of privacy under which a person has a right to refuse to undergo a genetic test and a notion of privacy under which a person has the right to prevent access to information about the results of a genetic test. It is the latter notion to which my argument is principally addressed. Although often conflated with the former notion, the latter notion is often argued for in literature on genetic privacy. *See, e.g.,* M.Z Makdisi, *Genetic Privacy: New Intrusion A New Tort?*, 34 CREIGHTON L. REV. 965, 987 (2001) ("Recognizing that one has the right to control what personal information is to be shared or to remain private appears to protect an inalienable human attribute associated with voluntary intimacy more than a severable property interest. . . . Some consider this foundation of human dignity an essential human value which

I am going to construct my argument in the context of the relationship between insurers and insureds. I'm doing that because that's my background and what my experience over these past sixteen years has involved. But I suspect that the same considerations may apply in other areas, in particular in connection with the relationship between employers and employees.

Let us start with the proposition that an insurer or an insurance company is a social construction—some sort of social device—that we have all decided to use in order to spread risks. We have, in other words, decided to spread risks by entering into mutual promises with insurers. Roughly the insurers promise that they are going to provide coverage for a described set of risks, and the insureds promise that they are going to pay the described premium.

The result is, in theory, through these mutual promises insureds are able to eliminate their risks of catastrophic loss and insurers are able to spread the cost of such risks equally throughout the population of policyholders. If the market mechanism works, that is exactly what will occur. If the market mechanism works, the premium amount should reflect the total risk assumed by the insurer and include some small further amount to reflect a compensation for the services that the insurer provides, sometimes called profit, which is ultimately distributed to the insurers' vendors, employees, shareholders, and in the case of some insurance companies—what are called mutual insurance companies—their policyholders.

That is the picture or theory of the way the mechanism of insurance is supposed to spread risk. I submit that given this picture or theory, the mechanism will only work if the promises that are made between the insurer and the insured are appropriate promises; that is, if the premium is right and the promised coverage is right in the sense that the one appropriately matches the other.

Now, these points may be elementary and obvious. I make them because the idea of genetic privacy in their context does not fit. By "genetic privacy" I mean the ability of one person to protect from disclosure to another information that that first person has about his or her own genetic constitution. If we introduce that notion of genetic privacy into the picture of the insurer/insured relationship, we undermine the ability of that relationship to spread risk.

If we introduce the notion of "genetic privacy" into the insurer/insured relationship, the result will be that the risks that the

---

recognizes each person as a separate individual and forms the basis of the right to be let alone.").

insurer covers have not been presented to the insurer with the result that the risk the insurer promises to assume from the policyholder is not appropriately tied to the premium the policyholder promises to pay. This can be seen by a very simple example, which fortunately is totally fictional. I want you to imagine that I obtain a review of my genetic constitution and that I find that I have the genetic variation that leads to Huntington disease. I understand that, if you have this genetic variation, there is nothing that you can do to prevent Huntington disease; and the only way you can get Huntington disease is if you have this genetic variation.

I now know to a certainty that unless I die of something else I am going to die after fifteen years of progressive physical and mental deterioration. And so what do I do? Like any rational person, I immediately go out and purchase the Cadillac version of health, home care, and nursing insurance so that no matter what happens I get the longest term and best health and nursing care. I pay whatever is asked, and I now know that no matter what happens I am going to be taken care of when this unfortunate event strikes.

Now, imagine that you have gone through the same test and you're a bit more fortunate than I am. You have found out that your genetic constitution is such that unless you are hit by a car you are going to die asleep at the age of 99 and 6 months.

Now, what are you going to do? Well, you are immediately going to sell every kind of insurance that you have that provides long-term care and long-term disability. You will not buy life insurance, that's for sure, and you are not going to have long-term care insurance either. At least, if you do it's only going to be a very modest kind.

What we have done, you and I, by pursuing our own rational interests, is, in effect, upset the insurance mechanism that we have determined to use in our society to spread risk. We have done this by hiding information about ourselves from the insurers. If we adopt a rule in our society enforcing the notion of "genetic privacy," our actions will be perfectly acceptable. There will be no right of insurers to request or insist upon disclosure of information regarding a person's genetic constitution, since genetic privacy permits a person to prevent the disclosure of that information to other persons, including insurers. The notion of genetic privacy, therefore, appears contrary to the theoretical underpinnings of the insurance mechanism that we have chosen to use to spread risk in our society.

Now, why did I say at the outset that the debate about whether there should be genetic privacy is a displaced debate? I think that we generally have the moral and ethical intuition that, given that we use

insurance to finance our health care, I should be permitted—even with my knowledge that I have the genetic variation leading to Huntington disease—to acquire the Cadillac version of insurance. Since we have this belief, there is a tendency to conclude that I should be able to protect the information that I have this genetic variation against disclosure to third parties, including potential insurers. But this conclusion in the context of that original insuring relationship that I described at the beginning appears incorrect. By refusing to disclose clearly relevant information about my genetic constitution to my insurer, I am undermining the insurance mechanism through which risk is spread. In a sense, I am like somebody who says, "I'm going to burn down my warehouse in three days, so I should acquire property insurance to cover it." Or, take a home owner, for instance, who has his house on the flood plains, sees that the rising flood waters are coming and says, "You know, I'd better get flood insurance."[2] What I am doing is similar. I am refusing to disclose material information that is motivating my decision to acquire insurance, just as the homeowner who sees the floods rising is.

The intuition, I think, that leads us to say that I should be able to acquire insurance without disclosing material information about my genetic constitution derives from an intuition about entitlement, not from an intuition about a right to privacy. I think we all generally have the intuition that if I have this debilitating disease I should be entitled to some sort of care. There should be some caring mechanism in society that will provide such service to me. We use this intuition about entitlement to conclude that I should have a right to prevent from disclosure to potential insurers information about my genetic constitution. The hope is that by preventing disclosure of this information, I will be able to use the insurance mechanism to obtain the care to which most of us believe I am entitled.

---

2. In general, losses are insurable only if they are fortuitous. As one treatise has explained, insurance is "predicated on the general proposition that coverage is provided for fortuitous losses and not for intended consequences." ROBERT E. KEETON & ALAN I. WIDISS, INSURANCE LAW § 5.4(a), at 497-98 (1988). Many courts have applied this principle in practice. *See, e.g.*, Univ. of Cincinnati v. Arkwright Mut. Ins. Co., 51 F.3d 1277, 1280 (6th Cir. 1995) (policyholder must show that the loss was the result of a fortuitous event); Intermetal Mexicana, S.A. v. Ins. Co. of N. Am., 866 F.2d 71, 75 (3d Cir. 1989) ("Every 'all-risk' contract of insurance contains an unnamed exclusion—the loss must be fortuitous in nature"); Fidelity & Guar. Ins. Underwriters, Inc. v. Allied Realty Co., Ltd., 384 S.E.2d 613, 615 (Va. 1989) (insurance "covers only *risks* and, as such, affords no coverage for a loss that is certain to occur"). By preventing the disclosure of information about my genetic constitution, I am, arguably, obtaining insurance for something that, according to these principles, should be uninsurable.

Most western democracies deal with the situation directly in terms of an entitlement to care rather than in terms of a right to genetic privacy. It appears that the debate about genetic privacy is, therefore, a displaced debate. It should be a debate about the entitlement to care, not a debate about the right to protect information from disclosure.

MS. SANDZA: Good afternoon. I'm Elizabeth Sandza with LeBoeuf, Lamb and I just want to follow up on a few points about insurance having spent my years—and I won't say how many—since law school, pretty much practicing in the insurance field. Even though when I was sitting out there I would have said, "No, not possible." It's a fascinating world, really; it's really a financial world.

And I have to say that discrimination does occur in the insurance industry, in the insurance world, and Lon sort of alluded to some of why it does, and I can tell you from first hand it occurs. This week I got a bill from my auto carrier of a thousand dollars just because we signed up our teenage child as a driver. So, in the context of insurance, discrimination is not necessarily bad and equality is not necessarily good. Think about the example of my teenage driver. Auto insurers should be able to discriminate and I've enjoyed this many years of not having to pay for that risk category of driver really. That hasn't been spread to me. Now it will be, but, God willing, in two years she'll pass out of that bubble and we'll go back to normal rates.

The law generally allows sex and age discrimination in insurance and even requires it in some instances,[3] but it generally forbids racial and genetic discrimination—so far, anyway.[4] And you can try to line up these regulations and these laws and these cases on what insurance discrimination is allowed and what isn't, and I can't make sense of it. I'm quite sorry to say, that I think in large measure it has come to where it is today because of social pressures in sort of a patchwork of regulations and that all goes back to how and why and where insurance is regulated.

Historically you should know, first of all, that insurance didn't use discrimination, and we're talking 150 years ago they had what was

3. *See* 2001 Cal. Legis. Serv. 253 (West) (renewing the applicability of § 790.03(f) of the California Insurance Code, which requires "differentials based upon the sex of the individual insured").

4. *See* Jill Gaulding, Note, *Race, Sex, and Genetic Discrimination in Insurance: What's Fair?*, 80 CORNELL L. REV. 1646, 1659 & n.86 (1995) [hereinafter Gaulding] (listing states with laws forbidding racial discrimination by insurance companies); *see also* Paul Steven Miller, *Is There a Pink Slip in My Genes*, 3 J. HEALTH CARE L. & POL'Y 225, 256-57 & n.236 (2000) [hereinafter Miller] (discussing state laws prohibiting insurance companies from discriminating on the basis of genetic information).

called assurance societies, and these were basically mutual life companies, and this was a situation where we would all agree to insure each other's lives, putting in the same amount of money. Well, because the population, some people were much older and some were much younger, pretty soon the younger people said, "What benefit am I getting?" and they left the societies and so the society to cover those people dying off at the top had to raise their rates. Middle-aged people started leaving the societies and the societies collapsed. So, that's why insurers went back to trying to draw a balance between risk factors and pricing. And all of this insurance discrimination has been challenged on several levels and I thought maybe you could just hear a little background on that.

First of all, there were several challenges under the federal and state Constitutions. Why doesn't the 14th Amendment require equal protection for people who buy insurance? Well, if you remember, to be protected under the Constitution, you need a state action and insurance companies are not state actors.[5] And that was even argued because they're very heavily regulated by the states. What they can and cannot do is pretty much dictated to them by the states. But the courts rejected that theory. They said, "No, that's not state action."

Okay, what about federal statutes? Can federal statutes prohibit insurance discrimination? So far they have not, and that is because Congress has favored state-level regulation of insurance since 1945 when it passed the McCarran-Ferguson Act.[6] So, therefore, if there's a federal statute, unless it specifically says it is our intention to also regulate insurance, that federal regulation will not regulate insurance.[7] The insurer will be regulated in the state instead. There is a slight departure of this federal statutory regulation under Title VII[8]—and this is a segue into the employment discrimination, and there were two landmark cases—one called the *City of Los Angeles v. Manhart*,[9] and the other one was *Arizona Governing Committee v. Norris*, where the Supreme Court said if the insurance benefit is provided by employers, then the employer cannot violate Title VII and discriminate.[10] So, that's sort of one chink in the armor of the state-

5. U.S. CONST. amend. XIV.
6. 15 U.S.C. §§ 1011-1015 (1994).
7. *See* 15 U.S.C. § 1012 (1994) ("No Act of Congress shall be construed to invalidate, impair, or supersede any law enacted by any State for the purpose of regulating the business of insurance, or which imposes a fee or tax upon such business, unless such Act specifically relates to the business of insurance").
8. 42 U.S.C. §§ 2000e to 2000e-17 (1994).
9. City of Los Angeles Dep't of Water & Power v. Manhart, 461 U.S. 951 (1983).
10. Ariz. Governing Comm. for Tax Deferred Annuity & Deferred Comp. Plans v. Norris, 463 U.S. 1073 (1983) (discussing applicability of Title VII to issues of

regulated insurance system.

Okay now, what can the states do? Well, the states can do just about anything. The states regulate insurance that's written in their state. They also regulate insurers located in their state. Okay, and we have, like I said, a patchwork quilt of laws forbidding what they refer to as unfair discrimination coming out of the states, and basically it's very mixed. But generally the states have passed laws forbidding race-based classification.[11] On sex, they're mixed. In Montana, you cannot discriminate and provide better or worse rates, based on sex, whereas in California you must.[12] So, you don't know what to expect.

With respect to genetic discrimination, there's a certain logic to allowing it because it certainly can be an indicator to a certain risk that you either want to not cover, you don't want to cover the person, or you want a price for it. On the other hand, political pressures being what they are, at least thirty states have already outlawed classification based on genetic testing for health insurance.[13] And as you know, President Bush has recommended even federal legislation, which would proclaim an intent to regulate insurance that would ban genetic testing for health insurance.[14] Well, guess what? The health insurance agency is not all that excited. Why? Because ninety-five percent of all health policies are group policies, and HIPAA already prohibits group policies from excluding coverage based on even family history and so, therefore, you can't use genetic profiling for group policies.[15] So, it's not a huge issue to the health industry, but something to think about is all these other coverages where it might make some sense.

What about life insurance? What about annuities? People who live longer—should they pay a lower rate? What about disability insurance? What about mortgage life insurance—something you pretty much have to have? Should you have to pay more if you show

---

insurance discrimination in the workplace).

11. *See* Gaulding, *supra* note 4 (discussing state prohibitions on insurance companies use of the insureds race as a factor in its decisions).

12. *See id.* at 1661 (discussing the variations in state law requirements and prohibitions on insurance companies' use of sex as a factor in its decision making).

13. *See* Miller, *supra* note 4, at 256-57 & n.236 (listing thirty-five states that prohibit the use of genetic classification in insurance).

14. Adriel Bettelheim, *Cures May Arise From Genome Mapping, But Congress Anticipates Headaches*, 2001 CONG. Q WKLY. 1505 (discussing George W. Bush's July 23, 2001 radio address during which the president called on Congress to ban the use of genetic information in the areas of employment and insurance).

15. *See* 29 U.S.C. § 1182(1) (1994) (setting out the Health Insurance Portability and Accountability Act which forbids insurance company use of medical history or genetic information in determining an individual's eligibility for participation in a group plan).

a genetic disposition for something? And what about nursing home care? What about automobile policies? What if you have a genetic disposition for alcoholism? Should your auto policy discriminate and charge to you as it would to someone with a drunk driving conviction? It will all be sorted out. It looks like most of it will be sorted out in the states, and I submit it will probably sorted through political pressures.

Thanks.

MR. WERNER: Good afternoon. My name is Michael Werner. I represent the Biotechnology Industry Organization. The acronym is BIO. We represent about a thousand biotech companies and academic institutions. Now, most of you may have known that Dr. Hudson and her colleagues at the NIH, as well as in private sector companies, mapped the human genome recently. This was one section of the genome that perhaps you hadn't heard much about. You can see, starting at the top right, looking at it, they found out the gene for people's reality-based TV fixation, willingness to drop $3.95 on a cup of coffee.[16] So, the genome reveals more and more about the human character.

Well, you know, we're all here because of this challenge that we face with genomic data. You've heard today, I'm sure, from lots of the speakers about the vast potential we have to use genomic data to improve human health, but of course all this information raises all of these very difficult legal and ethical issues, and a lot of public anxiety. Since the mapping of the genomes, the salience of this issue to the public has clearly gone up and you'll hear lots of folks who have responded to public opinion surveys state that they have been victims of some kind of genetic discrimination.

Speaking on behalf of our industry, we feel very strongly that we need to address these issues. The technology, that's used—genomic technology—again, has vast potential to improve human health, but if the public is afraid to use it, then all of this valuable knowledge will be squandered. So, since about 1996, BIO has had a very strongly-held policy that basically says that people's genetic information should be safeguarded against misuse.[17] So, one of the issues we've already heard about today is discrimination; what information should be protected; what information does not require protection; what

16. Mr. Werner showed a cartoon depicting a deciphered DNA helical structure which joked about the gene to buy expensive coffee.

17. *See* About BIO: Partner to a Dynamic Industry Coming of Age, *available at* http://www.bio.org/aboutbio/history.htm (describing the mission of BIO, including its policy stance on the ethical use of genetic information).

information should insurers be able to use for underwriting; and what information shouldn't they have access to? We've also heard that over the summer President Bush made an announcement that caught a lot of people by surprise. He called for some kind of legislative solution. In fact, there have been bills pending in Congress for a number of years on this subject. But, since the publishing of the genome and the mapping of the genome, this issue has taken on new urgency.

So, what does the biotech industry think? Well, again, we believe there should be legislation prohibiting discrimination, and providing safeguards against the misuse of genetic information. By the way, we would argue against the misuse of all personal medical information of which genetic information is just one component. But that's been the industry's view since 1996. On the other hand, we also think that legislation prohibiting discrimination has to do three other things. Legislation has to protect genomic data used in research. Researchers use this information. They need to have access to it. They need to be able to share it. That's the way we're going to figure out all of these health problems. We're going to figure out how to design the drugs, the biological products that are going to cure these diseases. We also need to make sure that when Congress drafts legislation or agencies draft regulations, the definitions and the terms they use are precise and up to date with technological developments. And, finally, there shouldn't be price controls. Our industry feels very strongly in other contexts that the government shouldn't regulate the price of our products, and we feel that that's appropriate for other markets as well.

I don't need to touch on this. You've already heard that HIPAA deals with the group health market.[18] Let me quickly touch on the three main proposals that are in play now. The Slaughter/Daschle Bill—also sponsored by Sen. Ted Kennedy—you can tell what it does by its title: Genetic Nondiscrimination in Health Insurance and Employment Act.[19] So it addresses discrimination in both the health insurance and employment contexts. And basically what they're trying to do is something that is very difficult legislatively. And you guys are fledgling lawyers so you can sort of appreciate how tough this is. They're trying to prevent discrimination against asymptomatic

18. *See* 29 U.S.C. §§ 1181-1184 (1994) (setting out legislation to regulate group health insurance plans).

19. S. 318, 107th Cong. (2001) (prohibiting a group health plan from denying eligibility to a group on the basis of protected genetic information about an individual in the group).

individuals who may go get a test and find out they carry a genetic trait for something that changes the statistical chances that they may, in fact, get some kind of disease later. So, that's the person they're trying to protect. They're not talking about somebody's current health status. They're talking about an asymptomatic person. They've got about 260 co-sponsors, so obviously if you do the math, more than enough to pass the House.[20] And probably close to thirty co-sponsors in the Senate.[21] From our perspective, things are pretty good with that bill, but there are no research protections.

Now, the big Republican bill is sponsored by two Republican senators—Olympia Snowe and Bill Frist.[22] The title—Genetic Information, Nondiscrimination in Health Insurance Act—tells you it does not address employment. It is just in the health insurance context. Again, it tries to expand on HIPAA, and addresses eligibility and premium adjustments for health insurance. It addresses individual market, whereas HIPAA focuses on the group market. From our perspective, again, its definitions are imprecise. The bill could include tests that cover current health status—not just the asymptomatic individual. Also, there are no research protections. And as I said, it does not apply to employment.

Now, over the summer, Congress was working on a bill, which you all have heard of because they've been working on it for about eight and a half years. It's called the Patients Bill of Rights.[23] And it has nothing to do with what we're talking about today. It had nothing to do with it until the very end of the debate when John Ensign, a relatively obscure senator from Nevada, stood up and offered an amendment banning genetic discrimination.[24] This was a complete surprise to Senators Olympia Snowe, Bill Frist, Ted Kennedy, Jim Jeffords—all of who had been working on this issue for a number of years. It basically tracks HIPAA and says that group plans and issuers

20. Bill Summary & Status for the 107th Congress, *available at* http://thomas.loc.gov/cgi-bin/bdquery/z?d107:h.r.00602 (listing the 256 cosponsors of the parallel House of Representatives Bill, H.R. 602, preventing discriminatory use of genetic information).

21. Bill Summary & Status for the 107th Congress, *available at* http://thomas.loc.gov/cgi-bin/bdquery/z?d107:s.00318 (listing the twenty-six cosponsors of the Bill in the Senate).

22. *See* Genetic Information, Nondiscrimination in Health Insurance Act of 2001, S. 382, 107th Cong. (2001) (setting out the provisions of the Republican sponsored bill to prohibit genetic discrimination in insurance coverage).

23. There are many different versions of this Bill. *See, e.g.*, Bipartisan Patient Protection Act, S. 1052, 107th Cong. (2001).

24. 147 Cong. Rec. S7123-25 (daily ed. June 28, 2001) (setting out the proposed amendment to the Patient's Bill of Rights to prevent the use of genetic information for purposes of insurance plan enrollment and rates).

cannot deny eligibility or adjust premiums. It doesn't apply to employment and doesn't have research protections. But it is now part of the Patients Bill of Rights.[25] So, what will happen with all these bills pending? Nothing. Now, in fairness to the supporters of this legislation, including the industry, it's because of September 11th and the aftermath of this tragic event. There was a lot of momentum but, frankly, as all of you who read the papers know, Congress is doing nothing these days except responding to terrorism attacks, anthrax and national security public health emergency-type issues. However, I would expect that if and when these issues calm, then next year the stage is set. You'll have industry, you'll have patient groups, you may even have the White House all pushing for some kind of legislative proposal, and I suspect, given that we've had a lot of conversations with folks, that we'll be able to iron out whatever differences there are, and you might see some legislation next year. Now, as was said by the previous speaker, for sure the insurance industry will be at the table. They have always expressed resistance to this, and we can expect that to happen again. So, it will be very contentious, but I think the stage is really set for next year.

Thanks very much.

PROF. CARLE: I'd like to start by thanking the Law Review for organizing this very important symposium, and also Nancy Segal, who took the initiative to organize this panel and make it coherent. We are very lucky that she has joined our community with her wealth of employment law experience. Nancy has directed me to put this panel discussion in the context of employment law in general, so that's what I'm planning to do here. I'm also going to try to be a bit provocative because that's what law professors like to do, and I want us to do a thought exercise in which we think about genetic discrimination in the workplace from maybe a different perspective than you all might be doing now. But I want to start by saying I think it's clear that there are many ways that employers can abuse genetic information, and if we look at the track record of the way that employers have used very unreliable kinds of testing, such as personality testing and lie detector testing before they were barred from doing so by legislation,[26] it seems, to me, clear that employers are going to do things that are not rational and make employment decisions based on very poor information. That's one way that we

25. *Id.* (showing that the Ensign's amendment was voted on and added to the proposed Patients Bill of Rights).

26. *See* 29 U.S.C. §§ 2001-2009 (1994) (prohibiting certain employers from using polygraph testing in some aspects of the employment process).

can be concerned about employers using genetic information in the employment context; if they use information that's unreliable, that's a poor indicator of performance or even risk, or they misunderstand the information and don't bother to get it right. But there's also another way in which we can be concerned about how employers use genetic information, and that is that they will use it in a way that's rational for the employer but that violates our public policy for one reason or another, and that I think is what's going on with the concerns about health insurance discrimination. Mr. Berk was saying that really it is rational to try to figure what your big risks are and exclude them from coverage. Or, if you don't want to exclude from coverage, to tailor your premiums to the nature of your risk pool. But because in the United States we rely on private employers to provide health insurance for our citizens, we don't want that to happen because we're going to end up with a big class of people who can't get health insurance. So, there's an important way in which our thinking about genetic discrimination and our understanding of American public policy more generally intersect, and I think that's an area that is interesting to think about.

And I'm sure that Commissioner Miller and Nancy will talk a lot about the really important work that the EEOC is doing around these discrimination issues, especially as they relate to disability discrimination and some important new cases, such as the Burlington Industries case, where an employer was using genetic testing to try to figure out which of its employees had a predisposition to carpal tunnel syndrome, apparently so that the employer could make the argument that for workers' compensation purposes, it didn't have to pay claims for workers who had carpal tunnel syndrome because they didn't get it from workplace conditions, but got it because they had a predisposition for it.[27] So, that's an example of the way that employers are likely to use and abuse genetic information.

But I want us to also think about this in another way, and I would suggest that really when we talk about genetic discrimination, we are not talking about a form of discrimination, but about a methodology for obtaining information about employees. And if that's true, I think the real question is what information do we want to allow employers to use in making decisions about which employees to hire, fire, promote, demote, grant benefits or detriments to in the workplace—and what information do we not want them to use.

---

27. Bhd. of Maint. of Way v. Burlington N. Santa Fe R.R. Co., 2001 WL 788738 (N.D. Iowa 2001).

Here's an example—here's my thought experiment. Imagine that you had an employer who's hiring for an engineering job and had two applicants. Both had good records from two different schools. One applicant went to a very fancy, expensive private school; the other applicant went to a cheaper state school, not nearly as well ranked. The employer doesn't know which person is going to be better as an engineer and so hires the person who went to the fancy school. All right, we would all say, that's fine. That's using all the information that's available to decide who's probably going to be better at doing this job. But imagine—and I don't think this is so far fetched, though perhaps people who are more expert in this will give me more information on this.

Imagine in the future it becomes possible to identify genetic markers for spatial ability. And I do think that they are now working on identifying the genes in which certain disorders exist, so it's not so unlikely that we will at some point be able to find genetic markers that correspond to certain kinds of cognitive talents. So, imagine this employer says, "Instead of just making the decision based on where the person went to school, I'm going to do a genetic test and I'm going to see which person has the marker for better spatial ability and hire that person."

Now, why is that any different from hiring on the basis of resume information? Is it more accurate? If it is more accurate, why does it still bother us? One of the reasons is that we think there's a privacy issue there—that is that the information being made available about ourselves is not voluntary. But I'm not volunteering the fact that I'm five-foot- six, that I have brown hair, that I'm over forty. You can tell that by looking at me. So, what's the difference between reading it off DNA or reading it off my appearance as I stand here before you, especially if for certain things you might get better information from DNA than you would from the impressions that people make in a job interview or on their resume or whatever? Here I'm not saying I think genetic discrimination is okay, but I am saying that I think we need to go underneath the methodology and re-examine what criteria we think are appropriate for employers to use in employment decisions, and we need to re-articulate what our policy reasons for that are. Genetic testing and genetic discrimination issues raise other really fascinating challenges to us in figuring out employment policy. One of them—and I'm just going to raise this as a question that I think the EEOC people will have excellent answers to—as I understand it, one of the wonderful things the EEOC has done in trying to curtail employers from using genetic information as a way of

engaging in disability-related discrimination is to say that to the extent that an employer is interested in certain genetic information, we're going to assume that that employer thinks that information is relevant to a possible disability. So we're going to define that under the Americans with Disabilities Act as somebody perceived as disabled.[28] But if it turns out that there isn't a clear sort of category divide between disability and differential abilities and if genetic testing can allow us to figure out some things about differential abilities, what does that do to our concept of disability? There's maybe a limited set of socially recognized disabilities that we are going to say you cannot discriminate on the basis of, but what about all of the other kinds of distinctions employers might be able to make using genetic information?

So, with that I will turn over the microphone to Commissioner Miller.

MR. MILLER: I'm going to stay down here, stay with the people. Thank you very much for inviting me to be a part of this esteemed panel, and my thanks to Ashley and Lisa for their hard work in organizing the program.

I am going to talk today about employment discrimination. One of the disadvantages of speaking at the end of the panel is that everybody, starting with Kathy Hudson, has already said everything that I want to say. On the other hand, one of the advantages of going last is that you have the opportunity to comment on what everybody has said before you. With that in mind, let me just make a couple of points about insurance that might be helpful for the overall discussion.

I think that insurance companies have thrived very well before the mapping of the human genome and that they figured out how to make money by insuring people. However, I do have a problem with the insurance industry selecting out people who have the wrong genetic marker and, therefore, will not ever be able to qualify for insurance. Creating a group of people that, through no fault of their own, are uninsurable when the United States Congress, with the support of the insurance industry has refused to pass nationalized health insurance legislation concerns me. Burning down a warehouse that one owns is a crime. Having a genetic predisposition for cancer is not.

Everybody has a genetic misspelling or a genetic predisposition for

28. 42 U.S.C. § 121102(2) (1994) (stating that an individual qualifies under the ADA if the employee is "regarded as" having a disability).

something. Sometimes, in these policy discussions, we assume that the world can be divided into two different groups of people—those with genetic predispositions to disease, and healthy people. But genetic technology is going to reveal something different. Everybody will have genetic markers for some condition or other. There are no "genetically healthy" people. For example, I may not have the Huntington's disease marker, but I may have a cancer genetic marker. You may have the marker for Huntington's disease, but not cancer. So, everybody will have genetic predispositions for something or other. This is important both in insurance and in employment because there is no group of healthy people out there that will not be affected by genetic markers. It is a mistake to separate things out in any other way.

Secondly, the vast majority of genetic markers, and Huntington's disease may be the exception, only tells one that you have a predisposition for the disease or medical condition. A particular marker may indicate only a higher risk for disease. For example, instead of having a ten percent risk of getting cancer, you would have a forty percent risk of getting cancer. That is all that a genetic marker indicates in most instances. A cop may not have the wrong genetic marker, but if he eats a dozen Dunkin' Donuts, smokes three packs of cigarettes, eats a couple of Krispy Kremes, and then goes home and belts down three scotches, well, he may have a high likelihood of having a heart attack regardless of what genetic markers he has.

Environmental factors are really, really important. It is critical that, as we discuss the problem of genetic discrimination, that we do not empower genetic information too much. Genetic markers are important but they are not the end-all and be-all. There are lots of environmental factors that come into play.

As the science of genetics explodes, and, as Kathy Hudson alluded to and described in her talk, as genetic information and genetic technology becomes more accessible and more affordable, the issue that I grapple with is how society protects its workers from the misuse of genetic information. My concern—and a concern that is shared, as evidenced by anecdotal stories and empirical evidence—is that if employers are allowed to consider genetic predisposition information in making employment decisions, workers may be excluded from employment opportunities for reasons that are wholly unrelated to their ability to do the job. Genetic discrimination means, in this context, an adverse employment action taken on the basis of an asymptomatic genetic predisposition, not on the basis of having a

disabling condition. I am not worried in this instance about people who have diabetes or who have cancer, but about somebody who has the marker that means an increased risk of having cancer. People who already have a disability, a symptomatic genetic mutation so to speak, are already covered under the law. In addition to worrying about the job discrimination aspects of genetic information, a potentially damaging by-product—one that I know that the biotech industry and pharmaceutical companies are very concerned about—is the fear of discrimination is going to make people reluctant to take advantage of a growing array of tests or therapies that may identify vulnerability to specific diseases. For example, somebody may not want to enter into a research protocol or may not want to get tested for something because of a fear of discrimination. I think that is something to be concerned about.

The Americans with Disabilities Act prohibits discrimination on the basis of disability.[29] The EEOC has stated that the ADA also covers asymptomatic genetic predisposition discrimination. In other words, somebody who is discriminated against on the job because of a particular genetic marker is considered disabled for purposes of standing under the ADA.[30] To further expand on Professor Carle's earlier point, it is unlawful to base employment decisions upon one's genetic predisposition, upon a probability rather than based upon one's present ability to do the job. Indeed, the entire rubric of employment civil rights laws, Title VII,[31] the Age Discrimination Act,[32] the ADA[33]—all are rooted in this same principle, that individuals in the workplace should be treated based upon their ability to do the job, and not based upon a fear or a myth or a stereotype about some other kind of characteristic.

People have discussed President Clinton's Executive Order.[34] In addition, we have heard talk—and we will hear more talk—about the legislative bills that are floating around up on the Hill, and President Bush's endorsement of the concept. One thing I would like to add is

29. 42 U.S.C. § 12112(a) (1994) ("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").

30. *See* EEOC COMPL. MAN. (BNA) § 902.8(a) (interpreting the regarded as prong of the definition of disability under the ADA as including those persons with a genetic predisposition for a disability).

31. 42 U.S.C. §§ 2000e-200e-17 (1994).

32. 29 U.S.C. §§ 621-634 (1994).

33. 42 U.S.C. §§ 12101-12213 (1994).

34. Exec. Order No. 13,145, 65 C.F.R. 6877 (2000) (prohibiting federal employers from discriminating on the basis of protected genetic information).

that whatever bill gets passed up on the Hill, it will come to my agency, the EEOC, to write the statute's regulations.

Let me just say one last thing about the *Burlington Northern* case, which was a case that got a lot of press.[35] It is the first genetic employment discrimination case. The facts are important because it moved the discussion—I think both in the mind of the general public and the policymakers from one of science fiction to reality. Burlington Northern Santa Fe is a big railroad. Somebody had the bright idea, "Gee-whiz, a lot of our workers are coming down with carpal tunnel, which means that we have to pay out money to those workers." Instead of trying to figure out why they were coming down with carpal tunnel, they decided to engage in a surreptitious program of testing employees for a marker that may be indicative of a predisposition for carpal tunnel syndrome. It was then going to use that as a reason for denying claims because, hey, they didn't get carpal tunnel from the workplace; they had a predisposition for it.[36]

The EEOC filed a lawsuit against Burlington Northern. The case was settled fairly quickly. The railroad agreed to halt the testing, and not to retaliate against employees. Interestingly enough, they signed on to advocate for the need for federal legislation to prohibit genetic discrimination in the workplace.[37]

Let me stop there because I want to get into the discussion. Thank you.

MS. SEGAL: Well, I should have known better than to organize the order so that I follow on Commissioner Miller's coattails. But, anyway as Professor Raskin said before, I'm currently legal director for the Program on Gender, Work and the Family, which has nothing to do with genetic discrimination—at least not yet—but this issue has seemed to follow me around and I wanted to just make a quick plug because our program is looking for a research assistant, so if anybody's interested please come talk to me after the session. I first started working on the issue of genetic discrimination when I went to work at the EEOC for an exceptionally brilliant person, Commissioner Paul Miller, and started working on an inter-agency work group that was assisting the Clinton White House in developing an Executive Order on genetic discrimination. The inter-agency work group included representatives from ten or twelve different

35. *Burlington Northern*, 2001 WL 788738.

36. *See* Discrimination: Burlington Northern-EEOC Pact Preserves Right to Damages for Genetic Job Testing, 76 DAILY LAB. REP. (BNA) at A-1 (Apr. 19, 2001) (discussing the background facts of the case).

37. *See id.* (reporting the terms of the out-of-court settlement between the unions and Burlington Northern).

federal agencies. The Keynote speaker here today at lunch, Kathy Hudson, was very involved in the process. As anybody who's been involved in negotiations involving multiple parties can imagine, negotiating this executive order with ten different federal agencies was quite a project. I worked on it for two and a half years and I believe that the project was underway for at least a year or two before that, so it was quite a drawn out process.

After that I went on to work as labor counsel to Senator Kennedy, and genetic discrimination was one of the issues that I was assigned to work on. Senator Kennedy is a strong proponent of protections against genetic discrimination in both insurance and employment. He's been a chief co-sponsor of Senator Daschle's bill on genetic discrimination. He also serves as chair of the Health, Education, and Labor Pension Committee, so he has quite a bit of control over the agenda of that committee.

What I wanted to focus on today, though, is what are the chances of getting these types of federal protections passed—and, to focus on the serious risks associated with leaving genetic information unregulated. And I think the other point that's been made that I just want to emphasize is that genetic information should be protected like race or sex since it has no impact on an individual's ability to perform his or her job. We have protections under the Americans with Disabilities Act, which provide that employers are not allowed to rely on medical information in making job decisions, or collect it or disclose it unless they can show that it has relationship to that individual's ability to perform the job.[38] So, it doesn't really make sense to not have that same protection for something like genetic information where protection is even more warranted, because it really has no relationship to someone's ability to do the job. It's only a predictor. So, I think it just can't be emphasized enough how important it is to have these protections.

Now, I would say that before September 11th, if someone had asked me what the prospects were of getting some genetic protections in place, I would have said they were excellent. There was a great deal of activity in the genetics area on the Hill, including numerous briefings and hearings. In fact, there was actually a hearing scheduled for this week. The President had issued his executive order, which although a bit ambiguous in terms of its enforcement,

38. 42 U.S.C. § 12112 (1994) (stating in regard to medical examinations and inquiries by employers, "a covered entity may make preemployment inquiries into the ability of an applicant to perform job-related functions," but otherwise may not use any such medical information).

explicitly stated the federal government's position that there needed to be greater protections in this area.

Senator Daschle's bill, which Senator Kennedy co-sponsored, had been introduced in the last two congresses and currently has 26 co-sponsors in the Senate.[39] Congresswoman Slaughter's bill,[40] which is similar but no longer identical to Senator Daschle's bill, has 255 co-sponsors in the House.[41] So, we were seeing a lot of congressional support.

We were also hearing from employer groups that they wanted to see some protections. Employers want some predictability in this area. They don't want this information. They don't want to be sued for having it or misusing it. And as one of the other speakers today noted, even President Bush has come out in favor of protections against misuse of genetic information in both insurance and employment. Senator Kennedy's staff was starting to work with Senator Jefford's staff to develop what we had hoped to be, at that time, a bipartisan bill on genetic discrimination.[42] So I really felt like the stars were in alignment for something to pass. And then there was September 11th. Everything changed, which couldn't be more apparent than this week when the House of Representatives closed down with Congress operating at undisclosed locations, and Congress for, obvious reasons, was required to shift its focus away from civil rights and privacy issues to the issue of securing the nation. And it's unlikely, as others have noted, that any activity will occur this year. However, like others on the panel, I'm hopeful that we'll see some activity in this area again next year. While some may claim that it's insensitive or even unpatriotic to continue to press for increased civil rights protections at this time, I couldn't disagree more. America is based on these rights and protections.

So, on that note I will turn the spotlight back on Professor Raskin.

PROF. RASKIN: Thank you very much.

The issues raised here could not be more fascinating. I want to offer some hostile questions to some people on the panel to get a debate going. Commissioner Miller, I thought I'd start with you because you were so eloquent and lucid, but I wonder if you really

39. Bill Summary & Status for the 107th Congress, *supra* note 21 (listing the twenty-six cosponsors of the Bill in the Senate).

40. H.R. 602, 107th Cong. (2001) (setting out the House of Representatives version of a proposed anti-genetic discrimination law).

41. Bill Summary & Status for the 107th Congress, *supra* note 20 (listing the 255 cosponsors of the House Bill).

42. *See supra* note 22 (discussing the Republican-sponsored version of a bill to prevent insurance discrimination on the basis of genetic information).

did give fair justice to the other side of the issue, and let me pose it to you this way. Let's separate, for the moment, insurance from employment because I think that they actually present two different kinds of cases. So, if I could ask you to talk about insurance for a second, understanding that it's not your field, but you ventured over to that side of the table to talk about it.

MR. MILLER: That's why I hated law school.

PROF. RASKIN: Why can't the insurance industry take into account individual genetic risk factors that are discernible by science, even if they're not a hundred percent certain—say they're sixty percent certain or forty percent certain. I'm sure they've got actuarial experts who were able to do the math to incorporate those levels of risk into particular premium costs that they're going to ask different people to pay. But say we know about a genetic risk factor in a life insurance policy, for example, Huntington's disease or breast cancer or alcoholism. If that is actual information that exists, why can't it be incorporated? And you say, "Well, there are environmental factors"—of course there are, and they try to take those into account just as well. In other words, they try to determine is the person a smoker, is the person a drinker, and so on. But why isn't it perfectly consistent with the whole logic of insurance to take into account all known risks? Or, are you trying to compensate for the lack of universal national health insurance, or national life insurance, or national auto insurance plan by preventing clearly relevant kinds of information from being used by particular companies?

MR. MILLER: Well, as Jamie may know, because we were in law school together, I never took an insurance class in law school.

However, with that caveat, as we say in Washington, let me just say this about that. My point is that we need to be very careful as we engage in these discussions about genetic information that we do not empower genetic markers with too much meaning, and that we recognize exactly what such information may be telling us about an individual, and what the information is not telling us about an individual. As I said, I think that even in the context of Huntington's disease, where some would say that there is a one hundred percent certainty that if you have the marker, you will develop Huntington's disease, it is still very unclear as to what the Huntington's disease is going to look like, how severe it is, when the onset is, and so on and so forth. For the vast, vast majority of these markers, we are only really talking about probabilities. Now, I know that there are many in the insurance industry that are concerned about this notion of

unequal knowledge. The mistake is when somebody goes out, finds out that they have something or that they are about to get something, and load up on their insurance without telling the insurance company. I think that those problems can be addressed, that those are problems that are floating out there and folks will figure out a way to deal with that kind of information. But I think that it is wholly problematic to exclude large groups of people from the insurance marketplace because all you're going to do is drive people away from taking tests that ultimately can help them. To flip it back into the employment context, for an employer to say, "Well, gee-whiz, I want to cut my insurance costs and therefore make sure nobody gets sick in my workplace, so I want to look through the medical information and figure out who has the genes for cancer, BRCA 1, BRCA 2—basically exclude the folks with cancer markers from my work place." But does that really get you anywhere? I mean, it doesn't really get you anywhere. You're basically having the employer make arbitrary decisions about what are going to be unacceptable diseases or markers to have and, ultimately, what are going to be acceptable markers to have because ultimately employers are going to have to hire somebody. Therefore I am concerned, especially in the employment context, but in other contexts also, that these genetic markers are being used as a filter to exclude people from large pools.

PROF. RASKIN: Let me shift down to the other side of the table there. It seems like the whole move toward using genetic testing as a way to exclude people from insurance or employment cuts against a very deeply ingrained aspect of American democratic ideology, which is an anti-hereditary principle. We are a nation conceived in insurgency against royalty and the idea that people pass political leadership down through the blood. The Constitution bans taints of blood, that is, people being made criminals by virtue of something that their parents did or their grandparents did.[43] And to what extent is your side really trying to reconstruct some kind of genetic hierarchy in this society by using information this way?

MR. MILLER: Genetic royalists.

MR. BERK: Genetic royalists, yes. Let me say I am not and I have never been a monarchist. But the question, I think, really comes down to a question of subsidies because the question really is, can somebody require me to subsidize somebody who has a marker, an unfortunate genetic marker? Assuming that I don't have any

43. U.S. CONST. art. III, § 3 ("No Attainder of Treason shall work Corruption of Blood, or Forfeiture except during the Life of the Person attainted").

unfortunate genetic markers, and that question really amounts to, in a sense, should not I be able to buy insurance that accurately reflects the risks that I'm trying to avoid?

PROF. RASKIN: But doesn't that cut against the whole idea of insurance? I mean, once you enter an insurance pool, aren't you by definition going to be insuring people who get things that you don't get and vice versa? And if you could know your own risks, wouldn't everybody just self-insure?

MR. BERK: If you could know your own risks and you had enough money, you still could not self-insure because the whole idea of insurance is to spread risk, and the whole question is what risk do you, as a policyholder, want to spread? Now, in most cases in connection with health insurance, this is not a serious issue because of federal legislation saying that if you leave a job, with any preexistent conditions, you are still able to take your insurance with you.

SPEAKER: [Question inaudible].

MR. BERK: Right, but the question for an individual who's trying to get insurance on their own is very real. What would happen, for instance, for somebody with a "clean" genetic bill of health is that they cannot get insurance for themselves without subsidizing somebody who does not have a "clean" genetic bill of health whatever that means. As Commissioner Miller said, if you actually look at the science, really what you're talking about is differences of probability among different people of maybe ten percent here, thirty, forty percent here. And so the question really becomes why shouldn't that kind of information be given to insurance companies so they can more accurately balance different individuals' risk classifications. I think the jargon is "medical underwriting." Insurance companies do, to some extent, "medical underwriting." They go to your house—if you want to get a life insurance policy, you'll find that they go to your house and they take your blood pressure and the nurse practitioner gives you a whole series of tests. If you want to buy life insurance you have to say that you do not smoke or else you will be put in a different category of risk.

In fact, in most states if you lie and say you don't smoke and you die within a year or some specified amount of time, your life insurance policy is void.[44] So why should you be able to refuse to disclose information about your genetic constitution? The issue

44. *See* Gary Schuman, *Misrepresentation of Smoking History in Life Insurance Applications*, 30 TORT & INS. L.J. 103, 120-21 (1994) (listing states that allow rescission of life insurance policies due to misrepresentation of the insured's smoking history).

proponents of genetic privacy have to answer is why should subsidizations caused by these failures to disclose disturb the workings of the market mechanism?

PROF. RASKIN: And I think the answer goes back to this point that we have a belief in our society that we shouldn't be drawing distinctions between different groups of people based on factors that they have no control over, even if they might be real factors in terms of their physical or mental or psychological constitutions.

MS. SANDZA: I think the insurance industry is sort of a paper tiger here and being used as a scapegoat because I really don't think it's as big an issue for them as everybody else seems to think who's a noninsurer because, first, in the health insurance field it's a very small piece of the market because ninety-five percent is group; and, secondly, as Lon just suggested, in the life insurance business after you've had your policy for two years it doesn't matter.[45] It doesn't matter if you lied; it doesn't matter if you're dying; it doesn't matter what your genetic makeup was so that, therefore, if you were to be tested at age twenty-five, that you were going to die at age seventy, it doesn't matter.

MR. MILLER: Well, that's great. I mean, the insurance industry is going to sign onto a genetic anti-discrimination bill for health insurance and life insurance. That's great.

MR. BERK: Genetic discrimination I think has to be distinguished from genetic privacy. What I would object to is the notion of genetic privacy. If everybody in society decides that they want the risk classifications for health insurance to be in such and such a way, then insurance companies would have to live with that. But the question of genetic privacy is the idea that a potential policyholder can hide material facts in order to obtain a lower risk classification than everybody in society has decided they should be in.

PROF. RASKIN: Do you really mean by that insurance companies should be allowed to require genetic testing as a condition for purchase of a policy?

MR. BERK: They are allowed to do that in some jurisdictions.[46]

PROF. RASKIN: Yes, but genetic privacy is sort of a red herring there because if the insurance companies have the power and want the information, they can say, "We're not going to sell you a policy

45. *See id.* at 130 (noting that most states only allow a two year contestable period for misrepresentations by the insured).

46. *See* Natalie E. Zindorf, Comment, *Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance*, 36 TULSA L.J. 703, 719-20 (2001) (noting that not all states prohibit the use of genetic information and that some specifically allow submission of favorable genetic testing).

until first you undergo this genetic test."

MR. BERK: Not everywhere. In Texas, for instance, they cannot use genetic information.[47] And even the definition of "genetic information" is very hard to come up with because we engage in genetic discriminations all the time. Unfortunately because of my genetics I'm not going to break a major league home run title. But somebody's going to do that because of his genetics or her genetics and get a huge sum of money for it.

PROF. RASKIN: But you wouldn't be excluded from pro baseball on the basis of a test, a genetic test.

MR. BERK: I am excluded on—well, what's the difference?

MR. MILLER: You want to be excluded on the basis of your ability, on the basis of your qualifications. I think that's a red herring. To say that "I'm never going to play NBA basketball because of genetics" —well, I'm not going to play NBA basketball because I'm not qualified to play NBA basketball. But, to the extent that I want to get a job in some company and that company says, "Oh, no, you've got a higher genetic risk for cancer and, therefore, we are going to exclude you" even though I am well-credentialed and qualified for that particular position, I think that that is very, very different. Again, the notion is that everybody's got something and so therefore, particularly in the employment context, it is a false choice to say that those who have no genetic risks or all of those who are genetically perfect or genetically free of disease want to get together and insure each other and exclude everybody that has genetic markers for disease. Well, there's not going to be anybody because you may not have Huntington's disease but you may have markers for all sorts of other stuff. So do all the cancer genetic marker folks get together and go to Aetna, and all the heart disease people go to another insurance company?

PROF. RASKIN: Well, let's take that question seriously. I mean, you might say people who have a twenty percent chance of dying by age fifty get together and have one insurance pool and they have another group of people who have a forty percent chance, a group of people with five percent, and presumably you would like to stack up the population in that way so that people who are actuarially in similar situations would be grouped together.

MR. BERK: I'm not saying that I'm a proponent of that.

PROF. RASKIN: I mean, that's what the market would do, and it

47. *See id.* at note 155 (listing Texas among states with legislation prohibiting the use of genetic testing in insurance).

should be allowed to work that way, don't you think?

MR. BERK: It remains a question whether you think the market should be allowed to work in that way or not, but the theory behind insurance I think—

PROF. RASKIN: Depends on whether you think there's such a thing as a market.

MR. BERK: Well, that's another question. The theory behind insurance is that yes, we should fix risk classifications and then let the market work accordingly. By inserting a notion of genetic privacy in the insurance context, you're undermining that theory.

MS. SEGAL: I just wanted to say that there are thirty-four states that now protect against genetic discrimination in the insurance context,[48] twenty-eight states that have protections against genetic discrimination in employment,[49] and I haven't heard a flood of complaints or problems resulting from the state legislation.

MR. BERK: Most of it is in the health insurance field I think, and there, because you have the group plans, you're not in a situation where it becomes a major issue. And also I think, time may lead to further issues. This whole question is in its infancy. Even though we've mapped the genome we may not know what the map shows.

PROF. CARLE: It seems to me that the problem with health insurance, even with group insurance, is that without legislative prohibitions against this, employers would want to go to insurance companies and say, "Look, we pre-screen everybody that we hire. You tell us which genetic markers you think make us increase the cost of insuring this risk pool and we'll screen those people out and we'll offer you a workforce that doesn't have those people in it and won't you give us a lower premium," and the health insurance company would say "Sure."

PROF. RASKIN: But, Susan, doesn't that go on all the time anyway with other types of risk factors? Environmental risk factors—I mean, take your example.

PROF. CARLE: Right, but that creates an incentive for employers to rid their workplaces of environmental hazards that are likely to produce higher health insurance costs.

PROF. RASKIN: Yes, but in an individual case it might not be accurate. I mean, I'm surprised that everybody just accepts so cavalierly the fact that insurance companies should be able to

48. *See id.* (listing the various states which regulate the use of genetic information in insurance).

49. *See id.* at note 110 (listing the states that prohibit workplace discrimination based on genetic information).

discriminate against young men, young women in auto insurance rates.

PROF. CARLE: Well, exactly. That's another point that I have about what you said. We do engage in all kinds of discrimination. We use certain indicators as predictive, and they're not predictive. But it is possible that there may be certain genetic indicators that are better predictors than things like age or gender. And I share the intuition that there's something wrong with reading DNA and then making decisions on the basis of it, but I think we need to articulate what that reason is beyond saying employers will use it irrationally because I think we also want to say that when even employers are using it rationally, if they're picking something that's a better predictor—or a health insurance company is picking a better predictor than age or gender or other things that health insurance companies are often allowed to use—that there's a reason why that shouldn't happen. We have to say, "What is the reason why even a rational decision based on genetic information or information that's obtained from DNA strands and not from some other indicator—why is that wrong?"

MS. SANDZA: I think that you raise a good point and maybe it's helping crystallize some sort of conclusion here, that most—not including age—other categories that insurance companies use are behavioral based as opposed to something inherent, such as drinking or smoking. That's one thing. And then I think another factor is that this genetic testing is just so very, very personal. And then, thirdly, the genetic testing is a predictor. It's not a known event. So, maybe that's what offends us. I would have to join and share your offense, but I can't predict whether or not how the laws will go in the states because, you know, we have a huge precedent for allowing discrimination in insurance, and there's even logic to it. But maybe this one's just over the edge.

MR. MILLER: But it is important to note that distinctions do not always rise to the level of discrimination. Simply because you create distinctions between groups does not mean that you are discriminating.

PROF. RASKIN: Betsy.

MS. SANDZA: Yes, I just wanted to add two points. One is that one of the differences between HIPAA and the federal bills that are being proposed is that the federal bills add a prohibition against requiring or requesting individuals to get a genetic test, a rule that HIPAA does not have, and that's something that people often point to as one of the holes in the existing regulatory framework.

And the second is just an observation. I think that the reason it feels different is not only because it is behavioral, it's that it's all this new technology. And it's the use and the development in what seems to be growing very, very quickly this development in application of technology as opposed to—you know, people are used to the idea that if you smoke it sounds like your premium should be more because we all sort of know that smoking causes cancer, or we think we do, whereas now it's not only that this stuff is more precise—on the one hand more precise but also on the other hand it just changes the statistics; it does not prove anything. I think also because we as a society have not figured out how to balance the possible benefits of these technologies and the use of the technology to—for example, you find out that your risk factor changes, so maybe you change your lifestyle, maybe you change your diet, maybe you go see your doctor more often then you would have otherwise. And yet all this technology could also be used in a way that seems harmful, and I think that's why everybody is grappling with this and that's why it feels different—because it's us trying to figure out, as a society, how we cope with the development of new technology.

PROF. RASKIN: Yes.

MS. SEGAL: I just want to further respond to Betsy's comment by borrowing some examples that Kathy's boss, Francis Collins, has used when I've heard him speak. One problem is that if you screen people on the basis of genetic information, which really goes against an important principle in America that people should be judged based on their abilities and their performance, you'd end up screening out people like Lou Gherig from being a ballplayer, and I forget who the composer was but, you know, famous . . .

MR. MILLER: Beethoven.

MS. SEGAL: Thank you—who was tone deaf and various others, and it just goes against the grain of what we believe in America that people should be based on their abilities, not on some prediction of what might happen to them in the future.

PROF. CARLE: But their abilities are also highly genetically influenced.

MS. SEGAL: But some people go beyond their genetic predisposition.

PROF. RASKIN: Well, the geneticists would say that's impossible, that by definition, you're just fulfilling some genetic predisposition or capacity that you have.

MR. MILLER: But any dean of admissions would say that that's likely. People who get low LSAT scores or high LSAT scores go on to

be either successful law students or successful lawyers or not. It is predictive, but only to a certain extent. One would not want their SAT score following them throughout their entire career. I wouldn't want mine to follow me around. I can only imagine that the President is about to nominate me to the Equal Employment Opportunity Commission, and looks at my SAT scores and says, "Oh, gee-whiz, but you only scored so-and-so on your SATs - you must not be very well-qualified for the Commissioner," and as a result, he decides to withdraw my nomination. Predictors can only predict, they do not determine.

PROF. RASKIN: The point I'm trying to make is that an SAT or LSAT doesn't determine what a person's potential limits are in terms of what they can do, but at least what the geneticists are saying is that everything that you can accomplish—you might not accomplish it but everything you can do is built into your genetic structure.

MR. MILLER: No, that is absolutely wrong, and credible geneticists are not saying that. There is a genetic component and there is an environmental component, and today we do not understand the relationship between the two. Certainly not everybody who has the BRCA gene, the breast cancer gene, for example, is going to get breast cancer. Not everybody with, you know—go down the list—is going to get that particular disease, and people may get lung cancer irrespective of smoking or genes or whatever. There are all sorts of factors that go into the mix, and I think it is unfair, particularly in the employment context, to empower this new piece of technology with such power that that's all you're looking at and everything else becomes irrelevant or falls away. That is why I think legislation . . .

PROF. RASKIN: Okay, let's just go down the line. Nancy.

MS. SEGAL: I'd like to defer to Kathy Hudson since none of us are geneticists, and I've heard Francis Collins say over and over again that genes cannot control what a person is going to become, so Kathy, if you would like to—I don't want to put you on the spot, but you know Francis' words, and you know this field better than anyone in this room, so . . .

DR. HUDSON: It's certainly true what I am going to be able to achieve. We are much, much more than the sum of our genetic parts.

MR. WERNER: The other thing here is they're also called policy objectives, I think, and one public policy reason for making this distinction, and perhaps if you want to even accept the argument that it's duplicative protection, is there may be value in giving people

peace of mind, so they get the tests, they take advantage of the technology because we think, as a society, there's value for people to find out more about their health status. So, on top of everything else, there might be sort of a counter-public policy reason why we might want to put those protections into law or regulation.

MR. BERK: I was going to say that there is a critical difference between employment and insurance, in that in employment I think the intuition is we want to judge people on the basis of their ability; insurance is really all about prediction. It doesn't matter what your ability there is because we're talking about what might happen and what the probabilities are.

PROF. RASKIN: Right, so the relevant question in employment decisions is, is the person able to do the job? And to succeed you could say that the genetic information is of little or no value to determine that. But, in the insurance context it might not be the whole story, but it might be one key data that you would want to include. Is that right?

MR. BERK: Yes.

PROF. RASKIN: Thank you.

MS. SEGAL: But if I could just say that there's nobody here with insurance knowledge on the employee side to rebut that, so just because we're being silent doesn't mean that there aren't some reasons . . .

MR. BERK: Silence doesn't mean assent.

MS. SEGAL: That's right, to also have protections in insurance.

MR. BERK: So stipulated.

PROF. RASKIN: Let's see, are there questions from our audience here?

SPEAKER: My question is directed at the insurance side of the table. Can you explain risk spreading?

MR. BERK: The law of large numbers suggests that the expected risk should equalize if there is a large enough population. By charging a premium that reflects that expected risk, an insurance company is able to spread risk.

The idea is that everybody can avoid catastrophic risk by taking on the average risk, and that will work if you have a large enough population. That's what I mean by risk spreading.

SPEAKER: [Question inaudible].

MR. BERK: That would work if everybody were required to buy insurance. But in our economy and except in the employment context—that's not something that we've been willing to do. And so you have the problem of adverse selection.

PROF. RASKIN: Let me ask you about that because you mentioned before the possibility that someone is going to object that they're forced into a pool with someone with a high genetic risk when they don't have it—they know they don't have it. Are people actually complaining about that? In other words, is that coming from policyholders?

MR. BERK: I've read a couple of Law Review articles where people complain about that, but I don't think in the real world that that's—and that's no criticism of these Law Review articles; they were very interesting—but I don't think that's to say that in the real world that's happened yet, I think that's because these issues are so new. But that does not mean we should not struggle with the issues and try to figure out how to address them.

DR. HUDSON: [Comment was inaudible].

PROF. RASKIN: Let me ask you about that. Do you mean as to the purchase of future policies, or do you mean these people have an obligation to tell the insurance company just so they're aware of it, but they're not going to be uninsured—

DR. HUDSON: Well, in the individual insurance market, they could be uninsured.

PROF. RASKIN: You mean they could?

DR. HUDSON: They could. So I'm at risk for developing X, Y, or Z, and I know that and these statutes are passed so the insured cannot know that. What is going to be the effect on the individual health care industry and am I going to opt in early or to protect myself, and the bottom line is that's good news to the health insurance companies, because the kinds of risks that we're talking about are risks of me at age forty developing X, Y, Z by the time I'm seventy-five, and it's definitely motivation for me to get insurance, which it does, and that is good for you because you're only going to insure me for three years. The average stick with one insurance plan is three years. So, in effect it's good for the insurance—very limited data on that, the genetics. They are doing some studies on the findings, but there are no data to suggest that people alter their insurance buying habits because of genetic risk.

PROF. CARLE: I also think that it's really important as we engage in this conversation about insurance and we've spent a lot of time on insurance to know that most people get their health insurance through their job, through their work, so there is a tremendous link, or spillover in relationship, between some of these insurance issues and somebody's ability to either stay employed or to gain employment, because in our country that's where people for the most

part get their insurance. So, while these issues are important in the insurance context, they also have an important impact in terms of employment.

PROF. RASKIN: No one has really talked about the privacy value just in—I mean, is there kind of a personal autonomy where privacy value and just not having to show this information or not give it up, even if it has some predictability?

MR. MILLER: Or not wanting to know, and I think that's really very, very important. In my family we have a very strong history of cancer, and there are tests out there that I can do that will tell me whether I have the "cancer gene" that other people in my family have. But there is no medical therapy available to fix the "cancer gene" or prevent cancer from occurring. There is nothing that I can do differently in my life as a result of knowing whether I have the cancer gene or not, and, quite frankly, I don't want to know that because if I do have that gene I don't want to be walking around knowing that I'm a ticking time bomb that maybe tomorrow, maybe this little bump is cancer. That is not the way I want to live. Other people may in fact want to know that information, but it's ultimately my choice, and I think that it's inappropriate for an insurance company, or an employer for that matter, to insist in order to be insured or in order to gain employment that I have to know information that I don't want to know. I think privacy includes the right not to know.

MS. SANDZA: A corollary to that is the AIDS testing for life insurance policies. In several states, while they allow the insurance companies to test for AIDS, which was not a predictive test but it was a current test, they did not require them—the insured himself didn't need to know, didn't have to know—the applicant. So, there was some precedent for that.

PROF. CARLE: I think the privacy issue is very important because in the private sector, if you don't live in a state that has in their state constitution a privacy right that extends to the private sector, really there is no privacy protection generally and, again, I think this is one of the intuitions that we can get at through genetic testing because it is so new and we are sort of squeamish about it—to suggest that employees really do have rights to privacy in all kinds of ways that we should recognize, not just through information that can be gained through genetic testing but other information, too, that's not relevant to the employer's ability to make decisions about their job performance.

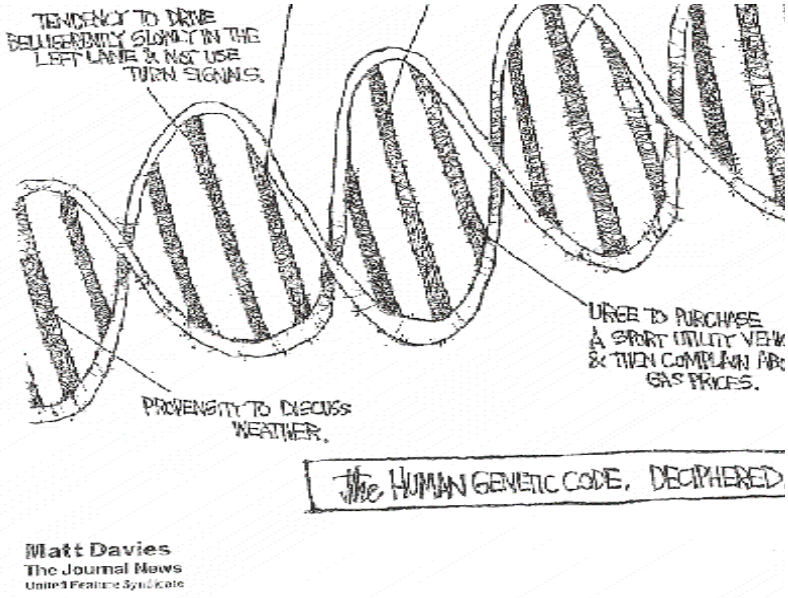
MR. BAILEY: I think we're going to have to wrap up officially.

PROF. RASKIN: Okay, it's over. Thank you for your hard work today.

(Whereupon, at 3:22 p.m., the PROCEEDINGS were adjourned.)

* * * * *

APPENDIX


TENDENCY TO DRIVE BELLIGERENTLY SLOWLY IN THE LEFT LANE & NOT USE TURN SIGNALS.
URGE TO PURCHASE A SPORT UTILITY VEHI & THEN COMPLAIN ABO GAS PRICES.
PROPENSITY TO DISCUSS WEATHER.
THE HUMAN GENETIC CODE, DECIPHERED
Matt Davies
The Journal News
United Feature Syndicate