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GENETIC DISCRIMINATION: DOES IT EXIST, AND WHAT ARE ITS IMPLICATIONS?

PAUL STEVEN MILLER¹

Yes. Once again, I stand between you and food and drink. I don't want to take up too much of your time, because you've heard a lot about what I had to say, but I was just reminded from Dr. Wiesner of a story. I was visiting my brother, my younger brother, and his young son came to him, to his father and to his uncle, and he happened to have gotten a poor report card that quarter, and he comes to his dad and his uncle and he says, "Father, I need you to sign this report card this quarter, but I have to tell you, I got some bad grades." And so my brother, Danny, says, "In our family, we really value education and this is really important." My brother begins to give his son a fatherly speech. Elan, his son, says, "Wait a second, father, I only have one question for you. "Do you think that my bad report card is a product of genetics or the environment?" I think that's really sort of where people are at in trying to sort through these issues.

This panel is Genetic Discrimination: Does It Exist, and What are its Implications? I just want to share with you some thoughts about that based upon all of the comments, each of which comes at this in a little bit of a different way.

Does genetic discrimination exist? Thus far, there have been no cases other than *Burlington Northern*² and maybe a couple of other cases which have been filed by plaintiffs in either federal or state court. Notwithstanding all of the statutes, there haven't been a tremendous amount of charges coming in, people coming to the EEOC [Equal Employment Opportunity Commission], or to respective state agencies and even filing charges. This fact confuses me, because I actually believe that genetic discrimination, as we've been talking about it, is happening more often in the real world than this charge flow would indicate.

I have spent a lot of time in the past year talking to the directors of state human rights commissions, and EEOC staff in our field, and I'm trying to understand why. I don't have any particular answers, but here are some thoughts that I do have.

One is that this is really new stuff. This is cutting edge technology and it may be that people aren't quite engaging in genetic testing, the kind of Athena Diagnostics genetic testing that we've been talking about. The second issue at play is that there may be people who are coming to plaintiffs' attorneys and saying, "Here's my story and here's what happened to me," and plaintiffs' attorneys, either because of a lack of understanding, a lack of the financial incentives in bringing a case, and the Supreme Court and the other federal courts consistent narrowing of the Americans with Disabilities Act, the plaintiffs' bar is basically rejecting these cases and just refusing to take them, because either there's no money or they don't think that they're winners because of the definitional problem.

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²*Sheet Metal Workers Int'l Ass'n v. Burlington Northern*, 736 F.2d 1250 (8th Cir. 1984).

I also think that there's a lack of knowledge out there by workers. Again, I mean, the *Burlington Northern* case is an exception on a number of different levels, but very rarely, if ever, does a company, I believe, come up to a worker and say, "Oh, by the way, here's what we're going to do, we're going to do some genetic testing on you and try to figure out what kind of whacky markers you have for all sorts of nefarious reasons."

People don't generally tell you whether they're doing genetic testing, I believe. Therefore, workers generally don't know that it is an issue or relevant or at the root of why they didn't get the promotion or why they weren't hired or why they were denied under the terms and conditions of employment.

So I think a number of those things are going on to figure out whether this exists or not. There is some subjective, anecdotal and objective data that's been done. None of that data is perfect, and I think it's certainly an area where new statistical data is really required to try to understand the nature of the problem out there.

The Genetic Alliance, which is a consortium of consumer-based genetic disability groups, has done or is in the process of doing a very, very extensive study on the nature of genetic discrimination in both employment and in insurance. People are anxiously awaiting the report of that study, and if you go to its website, which is <http://www.geneticalliance.org>, we may be able to get some bits and pieces about that to get a piece of it.

One comment I wanted to make with respect to something that Professor Davis said, and that had come up in an earlier set of remarks, is this concern about people, particularly in the insurance industry, finding out that they've got these genetic markers and stocking up on insurance to stack the deck in response to a bad genetic marker.

There's absolutely no evidence that it occurs out there, that it is the reaction. In fact, much of the evidence seems to point the other way, that people really don't go out and load up on long-term disability insurance or increase their health insurance in response to an asymptomatic genetic marker. Again, it's important that we try to figure out what's going on there.

In some senses, in my mind, it almost doesn't matter much whether or not genetic discrimination is occurring today. It doesn't really change the direction of what we're doing today and where we need to go, and that is because of the great potential for genetic discrimination in the future as the technology advances, as the economies come down and it becomes cheaper.

I think that we as a society, we, the EEOC as an enforcement agency, and industry need to get ahead of this curve, again, for two reasons. I think the law should prohibit such discrimination. Whether it is a huge problem or a small problem, it should be prohibited. And, secondly, I think that law, again, creates standards of conduct, and it's really important in an emerging and somewhat complicated area that policy and law exist to create some standards.

A couple of last thoughts about this. In large part, much of what is the problem of genetic discrimination, as many people have been talking about it today, exists because of the link between employment and health insurance or health coverage. Professor Davis did an excellent job of making that connection, and I just want to note that back in 1992 to 1995, when I worked in the White House, we actually tried to think about this health insurance issue, but we didn't get very far. I still have a whole stack of little plastic credit cards for the health insurance that can never be

taken away from you, though I haven't tried to show up and present that card at Johns Hopkins or at any other medical facility in order to get service.

But we tried that, and it will be interesting to see as technology progresses whether there, again, begins to be more momentum for looking at our health insurance. I actually believe as just a footnote, that you've got to deal with campaign finance reform before you'll ever be able to deal with health insurance, but that's actually another conference.

Be that as it may, the question is would the problem of genetic discrimination go away if you de-linked health insurance from employment – that is, assume that health insurance is not related to employment? Does the problem of genetic discrimination in employment go away? I think the answer is no, that the problem of genetic discrimination still doesn't go away because I think that employers will still act in stereotypical and bigoted and illegal ways in a sense based upon fears, myths and stereotypes, the same way that they react in illogical ways or irrational ways with respect to discrimination on the basis of race or gender or age or what have you. Discrimination, in a sense by its very nature is irrational, and so I don't think the problem goes away.

Some bad actors will still not want to hire or have people in their work force out of a fear that they may get sick and then may be out a lot, not be able to travel as much in their job, just general fear of sick people or people with chronic health problems, fear that people won't be focused on their jobs, particularly, and this is one slice of it that hasn't been raised yet, but I think it's really an important slice in the employment context – it's not just workers with genetic markers and the fear of chronic disease on the part of the worker, but parents.

Basically I think in some ways, employers are as or more concerned about a parent who is harboring a genetic marker that may give rise to a severely disabled child, and, therefore, that individual is going to be preoccupied with a disabled child at home, and, therefore, not be the quintessential worker on the work force.

What's the EEOC doing in a sense in light of all of this, both to protect workers and try to get a better handle on things? There are a couple of things.

One is that we're spending a lot of time talking to consumer groups, and trying to educate them both about the issue and put the issue within a civil rights framework. Again, Dr. Wiesner very correctly articulated the notion that this is on people's minds, whether they know the framework or not, and to be able to reach out to consumer groups to educate them about their rights is, I think, really, really important.

Secondarily, or in addition, educating the bar, particularly plaintiffs' bar on this issue, I think, is really, really important, and to share legal theories with plaintiffs' lawyers like Harry Zantville, to in a sense, as I like to do, think out loud about this, so that plaintiffs' lawyers, people can come together and really understand legal theories and figure out how we maneuver through these problems.

We have also been very actively engaged with industry, both the pharmaceutical industry and biotech industry, because I found there were a lot of people in the civil rights community, in academic science, in government science, policy makers, talking to each other about this emerging problem, and the 800-pound gorillas that didn't seem to be in the room in any of these discussions were the biotech industry and pharmaceutical industry. I think it's important that we reach out to PHARMA and BIO to explain to them what our concerns are, where we are, where we see the problems and to engage in a dialogue with them to sort of figure out how we can

maneuver and where there is consensus, because, particularly with legislation pending up on the Hill, the pharmaceutical industry, quite frankly, let's just call them a player.

And lastly, the EEOC has been very active in developing policy guidance. We had a very strong seat at the table when President Clinton drafted the genetic discrimination Executive Order back in February of 2000, and the EEOC has developed its policy guidance in that area, which is on our website at <http://www.eeoc.gov>, so if you want to take a look at some policy guidance that we've been doing, we've been active.

So, again, leaving some time for questions, I think that it does exist and there are implications and that's why it's important that we get together and we talk about it in the manner that we have today.

AUDIENCE: Considering that so many of the issues that come up with discrimination were based on genetics, for example, some diseases, some conditions are unique to racial groups. There are also a lot of cancers [which] are nothing more than mutations of genes over a period of time, which is part of the natural aging process.

Is there a way to define this type of discrimination in a composite type of class, like black women, that kind of thing that's happening in a lot of federal courts now?

Is there a way to do it that way, to actually use a compliance method of class (inaudible) to get in through just avoiding the ADA issues of (inaudible) testing, but actually get into a discrimination based on a composite type of class?

COMMISSIONER MILLER: There can be. That is certainly one strategy, and I think that you always try to expand your thinking when moving forward in a civil rights action, and there can be a very strong race/gender component to some of these fact patterns.

I would encourage you to take a look at a case, *Norman Bloodsaw v. Lawrence Berkley Labs*,³ which is a 9th Circuit case, which started out as an employment case, but the employment pieces were thrown out, and I actually question whether that would be done today in light of some new Supreme Court cases.

But there was a strong racial component around Sickle-Cell [Anemia] testing, and so on, and so there was a little bit of discussion. It turned out, it ended up to really be a privacy case. I talk about it in the article, which is in your materials, and I would encourage you to take a look at that case.

MR. ZANVILLE: There is, I think, a potentially fertile area to explore for those people who work in traditional labor sort of organized industries, whether it's under the Railway and Labor Act and the National Labor Relations Act.⁴ You may recall back from law school days, *Textile Workers v. Lincoln Mills*,⁵ which talked about the use of the federal common laws that would apply to the labor laws, and the Supreme Court in a number of cases has encouraged the bar to develop with the courts additional federal common law, especially in areas that cross over state lines that have significant national import.

³135 F.3d 1260 (9th Cir. 1998).

⁴Railway Labor Act, 45 USCS § 151 et. seq. (2003). National Labor Relations Act, 29 USCS § 141 et. seq.

⁵353 U.S. 448 (1957).

Now, can you imagine what could have more national import when you look at all federal laws that prohibit employers from making unilateral changes in working conditions and rules of employment. So to suddenly say, “We’re going to require genetic testing and tell you what the genetic testing is and how we’ll interpret it and not bargain about that,” and so if you said, as maybe on our case, “Well, we can sue the Burlington Northern in 22 states for various acts of violating state laws, but why not go to a federal court and say to the federal court under *Lincoln Mills*, why don’t we use federal common law?” This is a perfect application. Why drive everybody crazy everywhere doing administrative and judicial things when we really don’t have a cohesive policy.

I think there’s a lot of room to try to develop law that will protect workers in that regard, but caveat, there’s a new decision from the panel of the 7th Circuit in *Brown v. Soo Line*⁶ which preempts the ADA on the basis of federal labor law.

Anyway, I hope that answers your question.

AUDIENCE: One of the things that we would probably like is more information about the relationship of the genome to diseases, and right now we have, we have an understanding of the relationship between certain (inaudible) and particular diseases, but our knowledge is just at the very beginning.

One way to acquire more knowledge would be to do perspective studies, for example, of Burlington Northern employees. Take materials from them and see over 20 to 30 years how many of them get carpal-tunnel syndrome, and then look to see whether there’s a relationship between the genomes, those who get it and/or a difference between the genomes, those who get it and those who don’t.

How do, I guess, Commissioner Miller and Mr. Zanville feel about the participation of workers in that kind of study.

MR. ZANVILLE: A wonderful question. In the course of negotiations with the Burlington Northern, I suggested with the backing of my clients, that all railroad workers would, in fact, willingly agree to genetic monitoring, anonymous genetic monitoring under typical IRB kinds of things, because frankly, we want to know what’s happening to the workers and it’s not carpal-tunnel, it’s particular chemical exposures. We really want to know, and I will tell you that Burlington Northern took about 40 milliseconds to say, under no circumstances would we even think about doing something like that.

COMMISSIONER MILLER: Yes. I think that there is a lot of benefit here. Where the problem comes up is when, one, the company does it surreptitiously, and two, the company does it, again, without consent, and three, they’re using that information against workers and in an inappropriate way.

I think many people are very willing to step up to the plate and to participate in many of these studies, but they need to be done with the appropriate protocol, and I think that is on a lot of people’s minds.

PROFESSOR DAVIS: And I think also, too, to just broaden the answers to the question, it’s not just in an employment context. I mean, Dr. Wiesner pointed out all the fears that people have and the way in which this makes them retreat from testing that might be helpful to their health, and the other problem is that there are a lot of things we can’t find out because people are afraid to participate in research, and I

⁶See DeVito v. Chicago Park District, 270 F.3d 532 (2001).

suspect that even protestations of anonymity are often not enough, because there's just this general fear out there, and as a result there are just things that we're not finding out.

AUDIENCE: I'm afraid we may be confusing two kinds of research in the last few questions. There's research that looks at inherited genetic modifications or inherited genetic issues and how they may manifest themselves in a symptomatic disease over a lifetime, and that research is going on and there's actually a whole entrepreneurial vent now with companies creating stocks of tissue samples very carefully documented and following health records for decades, versus genetic monitoring, which refers to a different kind of thing.

There you're looking for acquired genetic damage, you're looking for various ways to measure the possibility that mutations have been (inaudible). If I were an employer, I might feel immoral, (inaudible) scared to death actually (inaudible) employee's work accumulating damage over a lifetime. But those are just very different, completely different forms of research.

I have a question then from yesterday. It was mentioned that a Cleveland company, Brush Wellman, was actually affirmatively doing some genetic testing and the suggestion was, I thought I understood, I'm not familiar with the case, this isn't my area of the law, that they were doing it for an altruistic reason, it was to benefit their employees.

Can somebody give some more explanation on that?

PROFESSOR DAVIS: That needs explanation.

AUDIENCE: I guess all I can come up with is perhaps they wanted to make sure that Workers' Comp was an exclusive remedy and that their employees couldn't sue them (inaudible). I guess this had to do with beryllium.

COMMISSIONER MILLER: The piece came from my remarks and it came out of an article that was in the *Chicago Tribune*, and I have the site somewhere in my remarks to the *Chicago Tribune*. I can point you to the article, and it was around beryllium, and what the – and people come into contact with beryllium, I guess, in certain job categories at Brush Wellman, and what I understood was happening is they were offering genetic testing, anonymous genetic testing to their employees, giving that information back to their employees and then letting the employees figure out what they wanted to do with that.

So, basically, really empowering the employees to say, "Well, here's a potential risk for certain people, here's a bunch of information about genetic markers for beryllium disease. We'll give you the test. We're not going to fire anybody that has the marker. We're not going to treat anyone adversely, we don't even want to know, incidentally, whether you have the marker or not, but if you want to know whether you are in a higher risk category, we will give you that information and you can make your own judgments."

That's how I understood the article.

AUDIENCE: So it was for all the best reasons.

PROFESSOR ENGEL: (Inaudible) When *Johnson Controls* came up to the Supreme Court, there was some insider information that Johnson Controls wanted the case to go to the Supreme Court because they wanted the decision that said, the Supreme Court told us to expose the (inaudible) so that they could develop a Workers' Comp case.

So with a beryllium exposure, you can imagine (inaudible) having [a] Workers' Comp claim, having developed the disease of beryllium, (inaudible) or whatever you

call it, and then the employer coming to them and saying as a defense, we offered you the opportunity to see if you have this gene. You chose not to do it, you can't get (inaudible), and I think that's a problem.

AUDIENCE: Maybe Workers' Comp, but they can't also then sue the employer civilly or –

PROFESSOR ENGEL: Oh, they probably could anyway.

AUDIENCE: Intentional tort. That's it.

PROFESSOR DAVIS: It's also worth remembering, if you're an employee, say, at Johnson Controls, maybe then, you know, if you leave Johnson Controls, then your choice then in that very role area was to do what, I don't know, flip burgers at McDonald's or something, and the same thing, if you leave Brush Wellman, you may also be leaving your healthcare insurance behind, and, you know, especially if you have a family, that's quite a risk-benefit ratio for any single employee to have to make.

MR. ZANVILLE: There's one more ramification to that, because those of who you know *Greenberg v. H & H Music*,⁷ which dealt with the question, and it was decided by the Supreme Court, yes, under ERISA, an employer could mid-stream change the benefits available under healthcare plans, so if, for example, if you have AIDS and you have a million dollar price tag somewhere in the future, they could mid-stream change the policy so their limit was \$5,000.

So if they can do that, if an employer, a self-insured employer can do that, what you're going to see, like we see in the transportation industry, is they split [a] company into risk groups. They take the high risk employees who have the least education, the least portability of employable skills, they put them in this one group of self-insureds, change the benefit plan, and bingo, they've saved themselves millions of dollars.

COMMISSIONER MILLER: You're such a cynic.

⁷McGann v. H & H Music Co., 946 F.2d 401 (5th Cir. 1991), *cert. denied*, *Greenberg v. H & H. Music co.*, 506 U.S. 981 (1992).

