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## Genetic Testing and Employment Litigation

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## GENETIC TESTING AND EMPLOYMENT LITIGATION

HARRY ZANVILLE<sup>1</sup>

Thank you very much, and just as a preface, I really appreciate and am a bit humbled to be invited to this conference. I'm surrounded by such bright people and such committed people. It's just a great experience for me.

Most major policy problems have their own vocabulary of context, and this case that I was involved in is no exception. About 60 percent of current reported occupational illnesses are from repetitive motion injuries. It's such a huge problem in American industry that about 80 percent of these cases, which are general laydown kind of cases, are contested in Workers' Compensation or in Federal Employers' Liability Act settings.<sup>2</sup>

This fact is compounded by the fact that most major employers believe they have plenary power to conduct medical tests, obtain medical information and use that information without restraint, kind of a provocative statement, but if you think about it it's true.

I think you'll also find it's provocative but true that many people who act as occupational medical providers, health insurance administrators, treating medical providers and even geneticists do not know or even respect the privacy rights of individual workers.

There are a number of very surprising studies that talk about the absolute amenability of these healthcare providers to turn over information without authority. So when we go over those kinds of facts and in some cases partial assumption together, you end up in a context where bad things can happen to good people, and that's what the Burlington Northern Santa Fe (BNSF) case really was about.

You should be aware that the case started, I think, when Athena Diagnostics doing some very interesting advertising. Athena Diagnostics is owned by Elan Pharmaceuticals Company, the third biggest pharmaceutical company in the world. Elan has invested millions of dollars in preparing to engage in the sale of genetic testing products and the sale of arguably treatment for genetic-based diseases.

Athena, whose claim to genetic fame first was their home testing kit for Alzheimer's disease advertised by direct mail over the Internet and in magazines had tests to predict who would get carpal-tunnel syndrome. Their research was based on, believe it or not, scientific work done by Dr. Philip Chance. Phil Chance is a wonderful guy who has been afflicted by genetic disease himself and who, according to Dr. Chance's research, was totally perverted by the people at Elan Pharmaceutical.

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<sup>1</sup>Represented the Brotherhood of Maintenance of Way Employees and the Brotherhood of Locomotive Engineers in *EEOC v. Burlington Northern Santa Fe Railroad Company*, which successfully challenged genetic testing of its employees. Until 1995, his law practice focused on complex legal problems in commercial, labor and employment law. In 1995, he began a sailing sabbatical and takes only isolated cases that have potentially important principles at issue. J.D., Case Western Reserve University.

<sup>2</sup>Federal Employers' Liability Act, 45 U.S.C. § 5 (2003).

Their advertising was on a website. You can look it up if you'd like to at <http://www.athenadiagnostics.com>, some wonderfully descriptive stuff where they talk about their pressure palsy neuropathy tests, and then they talked about it in very glowing terms. If you have carpal-tunnel syndrome, folks, we have the highest level of accuracy available in testing. Tests, of course, developed by Dr. Philip Chance and his colleagues, and they got a little picture, which I like to refer to as the genetic tarot card. It kind of looks like a little card, and it talks in scientific terms, but just enough that non-scientific people like occupational medical providers could understand, and they talk about, if you've got some of your workers who present with carpal-tunnel syndrome, that's an indication for testing.

Isn't this a wonderful test, and they give you all sorts of reasons why you should do this. Of course, these tests are wonderfully affordable, you know, somewhere between \$1,000 or \$3,000. They also engage in direct mailings, direct cold calls to corporations because they know that carpal-tunnel syndrome, repetitive injury stuff is a hot deal. There's a lot of money at stake.

Well, like all advertisers, sometimes the right person hears the right information. The Burlington Northern, like most of the nation's class one railroads, has a huge carpal-tunnel problem. They [cut] back on their maintenance forces by two-thirds and they're actually maintaining more track than they ever have because of their merger activity.

It's so bad on the railroads, that over a million dollars of lobbying was spent by the American Association of Railroads (AAR) to get an exemption from the then existing, the new OSHA ergonomics requirements. If they just kind of waited, they didn't have to spend that kind of money, but they nonetheless did. So they were exempted.

The Federal Railway Administration (FRA) has regulations that require accurate and complete reporting of occupational-related claimed injuries, not just injuries, just claims of injuries, and the nation's class one railroads simply lied to the FRA. They have said consistently as a group since about 1994, 1995, there is no more carpal-tunnel in the nation's railroads. It's the medical breakthrough that should have been reported in *Science Magazine* or in the *New England Journal of Medicine*, but it wasn't, and that's a little surprising. But that's how it is on the railroad. Then you say, "well, how could that possibly be?"

So that was the question I was asking of George Gavalla, who is director of safety at the FRA, when I got his reports that they did not want to release. But I found an ex-OSHA employee who was willing to give me the information, and there's a set of data, on all the AAR members: Norfolk Southern, the last reported carpal-tunnel injury was 1991; the Soo Line Railroad, their last one was 1993; Union Pacific, their last one was 1994, and it goes on, and the data doesn't lie. These are official documents, you know, federal documents. And the Burlington Northern in 1995 reported five cases of carpal-tunnel and that was the last time they reported any.

So it was wonderful that there was no more carpal-tunnel to worry about on the Burlington Northern Railroad. They had, however, some problems because, notwithstanding the fact they didn't have carpal-tunnel, they were settling carpal-tunnel cases like crazy with FELA.

There's one firm in Kansas City that in the year 2000, settled 5,000 cases of carpal-tunnel. Now, keep in mind, at the FRA, there's a \$5,000 minimum fine for

not reporting an occupational injury or illness. It didn't seem to matter to them. 5,000 cases in one firm alone. Well, how do you deal with that?

Well, they decided to use their occupational medical people to resolve their issues, and they were going to start to do this by genetic testing because they saw the Athena ads and they figured, well, they must be able to address them, and they had 125 cases they were just sure could have a genetic basis, and so even though there was no problem with genetic testing – no problem with carpal-tunnel, they decided that they were going to do genetic testing for the cause of these non-existing carpal-tunnel injuries.

We say well, how would a big corporation like BNSF ever be motivated to do such things. There's actually a little history. I mean, not all employers are purely benevolent. There's a case entitled *Sheet Metal Workers International Union v. Burlington Northern*, which is an Eighth Circuit case, 736 Fed. 2d, 1250.

In 1984, the Burlington Northern was caught on their railroad injury cases using their claims representatives, company people, to threaten the workers. If they hired a lawyer or retained a lawyer, it would jeopardize job security, promotions and cash advances. This was documented.

The Eighth Circuit described the conduct of the railroad as “disturbing and reprehensible,”<sup>3</sup> but found they were isolated incidents and surely couldn't represent what the corporation really was all about. They were trying to save money. That's what they were doing. Most of these railroad workers have a seventh grade education, one-third of them don't speak English. About 80 percent are not represented by lawyers when they settle their FELA claims.

So this is the kind of company and the history, the pedigree, that we're dealing with. So is it a surprise that the BNSF would want to be engaged in genetic testing? Not really.

When we blew the whistle with the FRA over the genetic testing and turned to the FRA and said, “why isn't this being reported,” the FRA questioned BNSF's officials, and according to the report back, and I quote, BNSF spokesman, Richard Russack, says, “The railroad does not report any of its claimed carpal-tunnel cases because the company determined that none of them were work-related.”

It's, by the way, the same reason they don't report asbestos cases, mesotheliomas, because, after all, these guys are working on brakes in their home garages, not on locomotive brakes. You know, it's okay.

By the way, the test that was done by Dr. Chance related to adolescents who, without any history of industrial repetitive-motion work, presented at the age of seven or eight with carpal-tunnel syndrome.

It had nothing to do with people who had 20 to 25 years of working on the rails with hand grinders and hydraulic jackhammers. That's the research that Athena was basing their work on.

There's also, and I'll take the liberty of quoting from a deposition of Dr. Girard, who is the Chief Medical Officer for the BNSF, who describes his attitude towards ethics and privacy in a deposition that was taken before our case.

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<sup>3</sup>Burlington Northern at 1254.

He says – regarding the question of confidentiality, he says, “Personally, I will call doctors and I’ll ask doctors questions about person’s functional ability and restrictions, as that information is necessary for me to determine fitness for duty.”

And the question from the lawyer, “Would you do that without a medical authorization from the employee”, and the answer was “Yes.” And then the question is, “Well, then in what states would you do that without medical authorization from an employee?” Answer: “I do it in any state the doctor resides.” So the company does business in 28 states, and they don’t care about privacy at all.

The question was asked, “Could a railroad compel a man on the subject of being fired if he refuses to agree to a medical examination which does not comport with common sense, and which was not consistent with medical standards? Could that employee be fired for not going?” The answer is, “Yes, it’s within the realm of possibility.”

The doctor, however, admitted that he did believe that he has an ethical responsibility, and that his responsibility is tied to a code of ethical conduct to those people engaged in occupational medicine, which is ironic because the society, professional society for people in occupational medicine has a specific provision that says, “You cannot engage in genetic testing without a written informed consent,” but he didn’t pay attention to that rule.

The doctor also at the end of the deposition talked about his job as the occupational medical provider for the BNSF, and he indicated that “The money we pay for the tort system is the cost of doing business and I want to try to keep it at a minimum.”

So their motives are not to pay injury claims, not necessarily do what’s in the interest of the injured worker. They engaged in this program, and one of the things they did is they sent a letter out to their local medical providers, and the letter says to them, “We are sending you a kit to do blood samples for genetic tests for pressure palsy. It’s going to be sent to a reference laboratory with kits provided by us. Please leave any decision about work-relatedness of these injuries to us. We will complete an ergonomic risk factor assessment independently. We only want you to confirm the diagnosis of carpal-tunnel and evaluate evidence of contributing health conditions, but not work-related.”

In other words, “Don’t tell us what really caused the injury, just tell us what we want to hear.” That’s the instructions to the doctor who is hands-on with the patients of these various states and, of course, the company that was employing these tertiary doctors when asked the question of what do you tell the employee, says, “Well, we do not explain or discuss the purpose of the test or evaluation of the employees unless specifically instructed to do so by the employers who sent the employee.” It’s a nice circle.

What we found out in this case is not one of the local doctors, not one of the local hospital facilities, not one of the local testing lab, nobody ever said, “Gee, this is wrong. We can’t do this.” Everybody in the system thought, “We know who is paying the bills, and we’re going to do what they want to do.”

And so what happened was the Burlington Northern did, in fact, commence to do first secret genetic testing of injured workers and then when they were caught at it says to the worker who caught them, Gary Avary and his wife, “Fine, we’re just going to coerce you: you don’t do it, you’re fired.”

That's when I was contacted. We stepped in, found the right place to go to court and were successful with, I will say, the help of a very large dog, the EEOC. If you want to get in a fight with a bully, put yourself in with a really good junkyard dog.

**COMMISSIONER MILLER:** Thank you, I think.

**MR. ZANVILLE:** And Commissioner Miller and his troops rallied to the cause and we are very grateful to them, because I don't think we would have achieved the level of success we did in the case as quickly without their help.

We were able to marshal the most wonderful cadre of professional geneticists and medical care people that you could ever imagine. I have never been involved in a case in all of the years I practiced law where people came out of the woodwork at no cost and said, "We want to provide for free any expertise that we can." It's incredible.

Francis Collins at NIH, at the Human Genome Project; Tony Holtzman at Johns Hopkins, Whyllie Burke, University of Washington Paul Billings. It was incredible and heartwarming, and so to the extent that someone was looking for Harry Potter before, those are those Harry Potter kind of people, because they stood up and said, this is the right thing to do and we're all going to stand in line to do the right thing. It was amazing.

And in the process of all of this, the media generated a lot of pressure on the Burlington Northern and its shareholders, and when the case got to be reported in five continents on every form of media you could imagine, Burlington Northern paid serious attention to the case and did the right thing.

There is a dynamic that, I think, is important. If someone knows how to turn this machine on, I'd like to use what I think might be a good diagram. Hopefully you all can see that, if I get out of the way. One of the things that we've thought about a lot is how can these cases actually happen, and the root of the problem, it seems to me at this point is, that the occupational medical provider in large corporations is the key to this.

There are lots of reasons why occupational medical departments want to engage in genetic testing. Some of them are to benefit themselves; that is, they want to be thought of as cutting edge kind of people. These are men and women who really think of themselves as kind of just ahead of the curve and want to go and do neat stuff. And what is neater than genetic research and finding out how to prevent injuries? So you have people who want to be ahead of the curve.

Then you have another set of people who don't want to be criticized for not being ahead of the curve, and so get positive and negative reasons for wanting to do what truthfully is medical experimentation; that is, collecting data, doing medical tests, which are probably unnecessary because they're not going to lead to anything useful, not telling patients about them, and that's the stuff that is prohibited by the Nuremberg code and the Helsinki principles embodied in international law, and in California, it's statutory.

So you have sort of personal kinds of issues, and so that's part of one of the circles there, which is, medical decisions are intended to benefit the occupational medical provider.

You then have another group of medical decisions that can be intended to benefit the employer. That is, there are some occupational doctors, including, I believe, Dr. Jarrard in our case who really took the position of, "Geez, why don't we just cut out a lot of costs." Why don't we go get this data as best we can, and then go to these uneducated workers who are unrepresented by counsel and say, "We're really sorry

about the carpal-tunnel you've got, but, you know, FELA is a negligence-based system. The fault was your parents. We didn't do this to you, and here, see, it's all in writing, and if they didn't like it, go and use the collective bargaining process to try to resolve this. You have a right to go hire your own geneticists, even though you only make \$18,000 a year and you live in Yankton, South Dakota and there's no geneticist for 900 miles. Okay. Go ahead and deal with this administratively." Well, you know it's not going to happen, and the local FELA lawyers can't help. They're out of their element. They have no idea.

So there's lot of ways that the circle of medical decisions that are intended to benefit the employer, the occupational medical providers, sort of militate, and, of course, then you've got that subset, and I would like to think it's a narrow subset, of medical decisions that are intended to harm the employee's interests.

There are a number of cases where you will find that doctors have taken a particular animosity to certain people, and it happened in our people with two of the employees who were specifically threatened, and it's pretty amazing. I've been given the stop sign.

Let me just share with you anecdotally one thing. The biggest trade magazine for the railroad industry is *Traffic World Magazine*, and *Traffic World* concluded in one of their articles after seeing what happened in our case and said two things: Maybe BNSF was using gene testing to discover the predisposition to become the ideal railroad employee, retires at 65 and dies within six months to save the company retirement fund. And they followed that up by saying, test for this, if the BNSF is so intent on testing the genes of its employees, we suggest they forget about identifying genes that predict carpal-tunnel and instead use their test to locate people who can actually track a shipment and tell the customer where their freight is.<sup>4</sup>

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<sup>4</sup>Frank N. Wilner, *Test Tube Ethics*, TRAFFIC WORLD, Feb. 19, 2001.