



# PROTECTING WORKERS FROM GENETIC DISCRIMINATION

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## HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH,  
EMPLOYMENT, LABOR AND PENSIONS

COMMITTEE ON

EDUCATION AND LABOR

U.S. HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

FIRST SESSION

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## C O N T E N T S

---

	Page
Hearing held on January 30, 2007 .....	1
Statement of Members:	
Andrews, Hon. Robert E., Chairman, Subcommittee on Health, Employment, Labor and Pensions .....	1
Biggert, Hon. Judy, a Representative in Congress from the State of Illinois .....	12
Prepared statement of .....	14
March of Dimes letter .....	61
Clarke, Hon. Yvette D, a Representative in Congress from the State of New York, prepared statement of .....	24
Hare, Hon. Phil, a Representative in Congress from the State of Illinois, prepared statement of .....	6
Kline, Hon. John, Senior Republican Member, Subcommittee on Health, Employment, Labor and Pensions .....	3
Prepared statement of .....	5
Slaughter, Hon. Louise McIntosh, a Representative in Congress from the State of New York .....	7
Prepared statement of .....	10
Statement of Witnesses:	
Escher, David, former employee, Burlington Northern Santa Fe Railroad .	35
Prepared statement of .....	38
Fishman, Burton J., partner, Fortney Scott LLP, Genetic Information Nondiscrimination in Employment (GINE) Coalition .....	45
Prepared statement of .....	47
Pearson, Harriet, vice president of corporate affairs and chief privacy officer, IBM Corp. ....	39
Prepared statement of .....	42
Rothenberg, Karen, Dean and Marjorie Cook Professor of Law, University of Maryland School of Law .....	30
Prepared statement of .....	33



mal record of the hearing. But you are welcome to speak extemporaneously, should you choose. You will then be asked questions by the members of the committee, as you just heard.

I want to introduce the witnesses.

Karen Rothenberg is the Dean and Marjorie Cook professor of law at the University of Maryland School of Law in Baltimore, Maryland. She has written and published and lectured extensively on the areas that are in front of us today.

And she has a niece in show business, she told me, which gives her a common interest with me.

Ms. Rothenberg, the reason I left to make a call is my daughter just got a callback, which I just heard. And you know the delight of hearing that news.

So anyone from Screen Actors Guild in the audience, pay due note to that point. [Laughter.]

David Escher, who has been with the committee before. This is his second appearance before the subcommittee. Mr. Escher was formally employed by the Burlington Northern Santa Fe Railroad. He is a devoted parent, as you will hear in his testimony about his concern about his children on how they were affected by his ordeal.

Welcome, Mr. Escher.

Ms. Harriet Pearson is the vice president for corporate affairs and the chief privacy officer for IBM, Incorporated, was educated at Princeton University in New Jersey, which explains a great deal about her success in life and her success at IBM. And we look forward to hearing her view as someone responsible for these issues in one of America's most important corporations.

And another, I believe, veteran of our committee, someone who has been an able and wise voice on issues that we have confronted for a long time is Burton Fishman, who is a partner in the Fortney Scott law firm, who is testifying on behalf of the Genetic Information Nondiscrimination and Employment Coalition, a long name indeed.

So, welcome.

And we would begin, Dean Rothenberg, with your testimony. We welcome you to the committee.

**STATEMENT OF KAREN ROTHENBERG, DEAN AND MARJORIE COOK PROFESSOR OF LAW, UNIVERSITY OF MARYLAND SCHOOL OF LAW**

Ms. ROTHENBERG. Thank you. Good morning, Chairman Andrews, members of the subcommittee. Thank you very much for the opportunity to be with you today.

As Chairman Andrews mentioned, I have been working for about the last 13 years on issues involving the ethical, legal, and social implications of genetic information. And I had the pleasure of chairing the committee on genetic information in the workplace, which was a joint workshop of NIH, the Department of Energy, and the National Action Plan on Breast Cancer in the late 1990s that, in fact, developed the framework for many of the state and federal legislative proposals. Most recently, my research has focused on the use of genetic information in the courtroom.

I would like to begin by putting in context our concerns about genetic discrimination in the workplace. Almost 20 years ago Con-

gress committed to investing in the human genome project because it shared the vision of a revolution, a revolution in medicine that would improve the health of all Americans. Their goal was not to provide health insurers and employers tools to weed out individuals that some day would generate large health-care costs.

To date, close to \$3.5 billion has been appropriated to fund genomic research for the American people. The return on this investment is substantial and the potential to transform medicine as we know it. But unless Congress acts to address these perils associated with unauthorized dissemination of genetic information, we may never be able to make the transition from the research laboratory to the doctor's office.

Even in the early days of the Human Genome Project people were concerned about social risks associated with research and anticipated that strong protections against misuse of genetic information would be established. Yet here we are 20 years later with enormous advances in scientists' ability to sequence and interpret DNA, and yet we are yet to achieve a federal law to safeguard genetic information. So the tremendous promise of genomics is hamstrung by fear.

First, how extensive is the fear? And why does it matter? I think in the interest of time I will just point out again that Congresswoman Slaughter mentioned a number of polls that have been taken in the last few years that substantiate that this fear is real. She also mentioned that genetic discrimination has a significant impact on biomedical research and potentially on health-care decision-making.

Although it has the promise to unlock new diagnosis and treatments and even to assist in pharmacogenetics and therapies tailored to individuals' genetic makeup, we will not be able to move forward, as mentioned earlier, unless individuals that might benefit are willing to participate in clinical trials. Fear that information will become available to and misused by employers or insurers has, in fact, chilled participation, including a 2003 NIH study of families at risk for a certain form of colon cancer.

Nearly half of the family members at 50 percent risk for inheriting a cancer-inducing mutation associated with colon cancer were not willing to participate in any aspect of the study because of fear of discrimination. Now, where does this come from? And is it justified? Perhaps it would be helpful to place these questions in historical context.

In the early 1920s Congress relied on genetic science and the genetic inferiority of racial, ethnic, and disadvantaged groups to restrict immigration into this country. It was in part the basis of restrictions in the immigration laws in the 1920s. State legislatures followed by promoting sterilization laws based on this same rationale. And eugenics was the scientific justification for killing millions during the holocaust.

During an early 1970s in this country African-Americans who were carriers for the gene mutation associated with sickle cell disease were denied insurance coverage, charged higher rates.

Chairman ANDREWS. Excuse me, Dean. The 5 minutes has expired, so if you could just briefly summarize.

Ms. ROTHENBERG. My goodness. Okay.

Chairman ANDREWS. I should have said this, that when the light starts to blink, that is the 1-minute warning.

Ms. ROTHENBERG. Okay. Well, I guess I wasn't looking up to see the blink.

Chairman ANDREWS. As a former law student, I have always wanted to ask a dean to stop talking. [Laughter.]

Ms. ROTHENBERG. Right.

Chairman ANDREWS. So I have now achieved one of my goals in life. [Laughter.]

Ms. ROTHENBERG. Well, I think now that I have moved past recent history and you have heard about Burlington, why don't I spend a little time, if I might, if I have another minute, on why we aren't seeing the cases and some of the concerns about the employers. Would that be all right?

Chairman ANDREWS. Of course. Yes, of course, Dean.

Ms. ROTHENBERG. Okay.

Chairman ANDREWS. And, of course, without objection, your statement has been entered into the record in full.

Ms. ROTHENBERG. Great, thank you.

So why do we have currently so little evidence of widespread discrimination? In fact, some have argued that is why we don't need the legislation. It is true that in recent years we have not been able to quantify the incidents of genetic discrimination. Why?

First, we don't have widespread utilization of genetic services. Second, individuals often will not know or understand the underlying basis for an insurance or employment decision. Third, without clear legal remedies, healthy individuals with a genetic predisposition for a medical condition may be adverse to risking their loss of privacy for themselves and their families by going public with a discrimination claim as opposed to with race or sex.

So don't be concerned about frivolous lawsuits. The burden is very difficult still for a plaintiff in these circumstances.

Finally, as a matter of law, discrimination cases that settle or resolve themselves at trial court levels never are formally reported. In my statement, I will delineate for you that currently under HIPPA, under the ADA, and under Title VII there are loopholes that this legislation attempts to close. And so, as a matter of public policy, if you ask me the question do you still need to pass a federal law, the answer would clearly be yes.

I would say in the rest of my testimony I will delineate for you what the collective wisdom is, what this legislation needs to include, and finally, the undue burden on the business community I would just like to end with two points.

First, if we are to assume that employers are complying with the applicable state laws currently on the books, then a federal law should not represent a significant new burden. Secondly, employers and those representing the insurance community have long maintained they are not currently using genetic information to determine eligibility or employment status. If so, a federal prohibition should not burden these practices. It would simply prevent misuse and integrate into compliance efforts.

To me I am not aware of any data that demonstrates increased cost to employers for complying with these state laws. So in summary, it is my hope that passage of a comprehensive law will move

us forward to honoring our commitment to improving our understanding of genetics and the positive impact on the health of all Americans.

Thank you.

[The statement of Ms. Rothenberg follows:]

**Prepared Statement of Karen Rothenberg, Dean and Marjorie Cook  
Professor of Law, University of Maryland School of Law**

Good morning, Chairman Andrews and members of the Subcommittee. Thank you for the opportunity to speak with you today. I am Karen H. Rothenberg, Dean, Marjorie Cook Professor of Law, and the founding Director of the Law & Health Care Program at the University of Maryland School of Law. Over the last decade or so, a primary area of my research has been on the ethical, legal, and social implications of genetic information and I have published numerous articles on genetics and public policy. I also chaired the Committee on Genetic Information and the Workplace (a joint project of the NIH-DOE Working Group and National Action Plan on Breast Cancer) that developed the framework for state and federal legislative proposals. Most recently, I co-authored an article in *Science* with my colleague Diane Hoffmann of the University of Maryland School of Law on the use of genetic information in the courtroom.

I would like to begin by putting in context our concerns about genetic discrimination in the workplace. Almost 20 years ago, Congress committed to investing in the Human Genome Project because it shared the vision of a revolution in medicine that would improve the health of all Americans. Their goal was not to provide health insurers and employers new tools to weed out individuals that might someday generate large health care costs. To date, close to three-and-a-half billion dollars has been appropriated to fund the promise of genomic research for the American people. The return on this investment is substantial and has the potential to transform medicine as we know it. But, unless Congress acts to address the perils associated with unauthorized dissemination of citizen's genetic information, we may never be able to make the transition from the research laboratory into the doctor's office.

Even in the early days of the Human Genome Project, people were concerned about the social risks associated with genetic research and anticipated that strong protections against misuse of genetic information would be established. Yet here we are almost 20 years later, with enormous advances in scientists' ability to sequence and interpret our DNA, and we have yet to achieve a federal law to safeguard genetic information. The tremendous promise of genomics is hamstrung by fear.

How extensive is this fear of genetic discrimination, and why does it matter?

- Fear of genetic discrimination is widespread in the American public. A 2006 survey by Cogent Research showed that 72 percent of respondents agreed the government should establish laws and regulations to protect the privacy of genetic information. Eighty-five percent believed that without a specific law on point, employers will discriminate. Sixty-four percent believed that insurance companies will do everything possible to use genetic information to deny health coverage. Recent polls conducted by the Wall Street Journal Online/Harris Interactive Healthcare and the Genetics and Public Policy Center showed similar results.

- Fear of genetic discrimination has a negative impact on biomedical research and potentially, healthcare decision making. Genetic research holds tremendous promise to unlock new diagnoses and new treatments, and even to assist in the creation of pharmaceutical therapies tailored to an individual's genetic makeup. However, scientific research and development cannot progress without clinical trials, and these trials can move forward only if individuals who could benefit are willing to participate. Fear that information will become available to and be misused by health insurers or employers has chilled participation in many studies of genetic conditions. For example, in a 2003 NIH study of families at risk for heredity nonpolyposis colorectal cancer (HNPCC), the number one concern expressed by participants regarding genetic testing was concern about losing health insurance should the knowledge of their genetic test result be divulged or fall into the "wrong hands". Thirty-nine percent of participants cited this as the most distressing issue relating to genetic testing. Nearly half of family members at 50 percent risk for inheriting a cancer-inducing mutation were not willing to participate in any aspect of the study because of their fear of discrimination.

Where does this fear of genetic discrimination come from; and is it justified?

Perhaps it would be helpful to place these questions in historical context. In the early 1900's, Congress relied on the use of "genetic science" and the "genetic inferiority" of racial, ethnic, and disadvantaged groups to restrict their immigration into

this country. State legislatures promoted sterilization laws based on the same rationale and eugenics was the “scientific justification” for killing millions during the Holocaust. During the early 1970’s, African Americans who were carriers for the gene mutation associated with sickle cell disease were denied insurance coverage, charged higher rates, and lost their jobs. More recently, the Burlington Northern Santa Fe Railway Company paid up to \$2.2 million to settle a 2002 lawsuit brought by employees who were secretly tested for a genetic variation purported to be associated with carpal tunnel syndrome.

Nevertheless, because there is currently little evidence of major problems with widespread discrimination, some might argue that there is no need for legislation. It is true that in recent years we have not been able to quantify the incidence of genetic discrimination. Why? First, we do not have widespread utilization of genetic services. Second, individuals often will not know or understand the underlying basis for an insurance or employment decision. Third, without clear legal remedies, healthy individuals with a genetic predisposition for a medical condition may be averse to risking loss of privacy for themselves and their families by going public with a discrimination claim, a greater risk than if the claim were based on race or sex. Finally, there may in fact be discrimination cases settled or resolved at the trial court levels that are never formally reported.

This raises an interesting public policy question: is it prudent to pass preventive federal legislation based on a fear of genetic discrimination? I would argue “yes,” if we are to fully benefit from the promise of genetic research.

Over the last decade, most states have enacted genetic nondiscrimination legislation, although the scope of protection varies widely. Forty-one states have passed laws on discrimination in the individual health insurance market and thirty-four states have passed laws on genetic discrimination in the workplace. There have also been patchwork approaches at the federal level. For example, President Clinton’s Executive Order 13145 protects federal employees from genetic discrimination in the workplace. Federal laws such as HIPAA, the ADA, and Title VII of the Civil Rights Acts may provide some protection, but there remain loopholes and gaps in coverage:

- HIPAA prohibits raising rates for or denying coverage to an individual based on genetic information within the group coverage setting, but HIPAA protections are limited to only the group market. It does not cover individual insurance plans. The Federal Privacy Rule, authorized by HIPAA, protects the use and disclosure of individually identifiable health information, including genetic information. The Rule does not prohibit the use of genetic information in underwriting. If a company determines that the individual is likely to make future claims, they could be charged higher premiums or denied coverage.

- The ADA was designed to protect those individuals who are living with a disability. The ADA defines disability as 1) a physical or mental impairment that substantially limits one or more of the major life activities of an individual; 2) a record of such impairment; or 3) being regarded as having such an impairment. While the ADA provides protections for people who have current disabling genetic illnesses, it is not at all clear whether the law covers individuals who have a genetic mutation that predisposes them to disease. Although guidance issued by the Equal Employment Opportunity Commission (EEOC) suggested a number of years ago that the ADA could apply in situations where an employer treats or regards an employee as impaired based on their genetic makeup, no court has ruled specifically on this issue. To the contrary, recent court cases have established a general trend of narrowing the ADA’s scope stretching the ADA’s definition of “impairment” to cover genetic predisposition to disease is inconsistent with the current judicial interpretation of the ADA.

- It is not clear whether Title VII of the 1964 Civil Rights Act would provide protection for those claiming genetic discrimination in most circumstances. Protection under this law is available only where an employer engages in discrimination based on a genetic trait that is substantially related to a particular race or ethnic group.

Thus, there is no uniform protection against the use of, misuse of, and access to genetic information in the workplace. As a matter of public policy, we still need to achieve a comprehensive approach that includes the following:

- (1) Employers should be prohibited from using genetic information in hiring, firing, and determination of employee benefits.

- (2) Employers should be prohibited from requesting or requiring collection or disclosure of genetic information unless they can show that the disclosure is relevant to the job. This is a very high standard and one that will rarely be met. Written and informed consent should be collected for each request, collection, or disclosure of genetic information.

(3) Employers should be restricted from access to genetic information contained in medical records released as a condition of employment, in claims filed for health care benefits, or any other sources.

(4) Employers should be prohibited from releasing genetic information without prior written authorization of the individual for each and every disclosure.

(5) Employers who violate these provisions should be subject to strong enforcement mechanisms, including a private right of action.

I understand that there might be concern that new federal legislation may place an undue burden on the business community. This is unlikely for two reasons: First, if we are to assume that employers are complying with applicable state laws then a federal law should not represent a significant new burden. Second, employers and those representing the insurance community have long maintained that they are not currently using genetic information to determine eligibility or employment status. If so, a federal prohibition should not burden their business practices. It would simply prevent the misuse of genetic information and be integrated into their legal compliance efforts. I am not aware of any data that demonstrates increased costs to employers for complying with these state laws.

In conclusion, the era of genomic medicine is here, but fear continues to paralyze its future. In the words of Dr. Francis Collins, Director of the NIH Human Genome Research Institute:

Unless Americans are convinced that their genetic information will not be used against them, the era of personalized medicine may never come to pass. The result would be a continuation of the current one-size-fits-all medicine, ignoring the abundant scientific evidence that the genetic differences among people help explain why some patients benefit from a therapy and, while some do not, and why some patients suffer severe adverse effects from a medication, while others do not.

It is my hope that passage of comprehensive federal legislation will move us forward to honoring our commitment to improving our understanding of genetics and its positive impact on the health of all Americans.

Thank you. I welcome your questions.

Chairman ANDREWS. Thank you very, very much.

Ms. ROTHENBERG. I welcome your questions.

Chairman ANDREWS. We appreciate it.

Mr. Escher, welcome to the committee. Welcome back to the committee. Your written statement has been entered into the record. And we welcome your testimony.

~~**STATEMENT OF DAVID ESCHER, FORMER EMPLOYEE,  
BURLINGTON NORTHERN SANTA FE RAILROAD**~~

~~Mr. ESCHER. Well, thank you. It is nice to be back here again. My name is Dave Escher. I am now 52 years old and had been employed by Burlington Northern Santa Fe Railroad for over 26 years as well as a member of the Brotherhood of Maintenance of Way during that time.~~

~~I was born and raised in Herndon, Kansas, a small northwestern town in Kansas with a population of 200 people. I graduated from high school in 1972, began my career with Burlington Northern in 1976 and abruptly ended that career in the year 2002.~~

~~I married my wife, Deb, in 1986. I have three daughters, Kelsey, Karen, Kristen. We now live in Reno, Nevada, after relocating 3.5 years ago from McCook, Nebraska.~~

~~My jobs within the company during that time included such positions as a laborer, truck driver, assistant foreman, machine operator and foreman. I was appointed to the Division Safety Committee and continued to serve on that committee for over 12 years. I held such positions as maintenance of way representative, vice chairman, and then safety and health and rural facilitator, up to the time of my departure from the company.~~

## ENDNOTES

<sup>1</sup> Title I of the Genetic Information Nondiscrimination Act addresses issues related to genetics and insurance coverage. Although certain individual Coalition members may have views on Title I, the Coalition's comments are limited to Title II of the bill.

<sup>2</sup> *EEOC v. Burlington Northern Santa Fe Railroad* (N.D. Ia., settled April 18, 2001).

<sup>3</sup> “[n]othing in this order shall be construed to \* \* \* require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program.”; 1-402(b)

<sup>4</sup> We should recognize, however, that there may be perfectly valid and non-discriminatory reasons for an employer to consider an employee's genetic information in order to ensure that the employee is working in an environment that would not exacerbate the employee's genetic predisposition to an illness or other health condition. The ADA recognizes that an employer may impose the qualification standard that an employee not pose a “direct threat” to the health or safety of others in the workplace. 42 U.S.C. Sec. 12112(b). The EEOC has expanded this statutory definition to include the individual with a disability. 29 C.F.R. Sec. 1630.2(r). Protection of a worker may mean that for his or her health and the safety of others, the individual should not be assigned to a job. In *Echazabal v. Chevron*, 536 U.S. 73 (2002), the Supreme Court unanimously ruled that the EEOC's interpretation was correct and that an employer may legitimately object to idly permitting an employee's self-inflicted exposure to injury or worse.

<sup>5</sup> The ADA authorizes disclosure of medical information obtained from a conditional medical examination only in the following circumstances:

- To supervisors and managers who need to be informed about necessary restrictions on the work duties of the employee and any necessary accommodation;
- To first aid and safety personnel; and
- To government officials investigating compliance with the ADA.

<sup>6</sup> An exception may arise where federal regulations, such as those promulgated by OSHA, would require an employer to engage in medical monitoring of employees. See, e.g., 29 U.S.C. 655(c)(7) (providing for the monitoring of employee exposure for employee safety).

<sup>7</sup> See *Cossette v. Minnesota Power & Light Co.*, 188 F.3d 964 (8th Cir. 1999); *Griffin v. Steel Tech, Inc.*, 160 F.3d 591, 594 (10th Cir. 1998); *Fredenburg v. Contra Costa County Dept. of Health Services*, 172 F.3d 1176, 1182 (9th Cir. 1999).

Chairman ANDREWS. Thank you very much, Mr. Fishman.

Thank you to each of our four witnesses for an outstanding contribution to discussion.

Dean Rothenberg, I would like to start with you, if you would. Mr. Fishman, in his written testimony, expresses the view that the bill that Ms. Slaughter and Ms. Biggert have introduced would penalize the flow of genetic information and therefore, retard and prohibit scientific progress.

Do you agree with that conclusion? I assume you don't. And if you disagree, explain to us the basis for your disagreement.

Ms. ROTHENBERG. I don't understand it. I mean, so maybe we could have a further explanation of it. But basically we have a lot of information and data that for whatever reason we are paralyzed and we are not reaching the promise of where we need to go.

And if we currently have 34 states that have laws where supposedly there aren't any cases being brought, his argument would be well, that must mean there is no discrimination. Another way of looking at it is we may not be getting the word out or enforcing what needs to get done. So that—

Chairman ANDREWS. Do you think it is more likely that the flow of genetic information for laudable purposes, for research—do you think there is more of a problem with it being retarded by people being afraid to sign up for clinical trials or by the limitations put on employer use of the material in this bill?

Ms. ROTHENBERG. Well, what I think at the very basis of this bill and the very ethical principle we need to remember is if, in fact, there is an understanding that an employee thinks that information is going to help them, their health, their well-being, their ability to do the job, the law provides for there to be written authorization and consent. If we listened to this story, it was about doing

something behind someone's back. It was doing something in secrecy.

And one of the arguments of why we may not have more of this or we don't know about it is because it may be being done. He happened to have found out. And that is why there is some narrowing or restricting of access or putting penalties associated with it because you are totally shifting the burden for him to have to have figured it out that it was being done.

Chairman ANDREWS. Just as we are obviously all sympathetic to protect the interests of Mr. Escher and people like him, I think we are also all sympathetic to the concerns that Mr. Fishman raises about not wanting to create undue burdens on business enterprises and employers. And I think Ms. Biggert has paid particular attention to that.

I wanted to ask, Ms. Pearson, you, Mr. Fishman in his testimony talks about real burdens and actual costs that would be visited upon employers should the legislation be adopted. Have you experienced any of those real burdens and actual costs in implementing the policy at IBM?

Ms. PEARSON. It has been about a year-and-a-half since we instituted our global policy. And I can't say we have experienced anything in our own policy. Our own policy is fairly broad. It talks about nondiscrimination in our employment decisions and health insurance decisions. It is a global policy. We have not experienced any significant costs.

We have studied the legislation that has been discussed today. We do have some observations on some of the issues in terms of practical, you know, implementation, which are reflected in my written statements and I have touched on.

You know, implementation, for example, segregated record keeping—if you get into specifics and point to certain things that are not related to the principle here, which is prevention of harm to all of us, prevention of harm in terms of employment or health insurance, you know, good minds can come to agreement on that. But overall, we have not—

Chairman ANDREWS. Right.

Ms. Pearson, is there anything in the bill that we have been talking about today that would in any way materially alter the business practices of IBM, given the fact you have adopted this policy already?

Ms. PEARSON. We have looked at the bill, and I can't say that there is.

Chairman ANDREWS. Mr. Escher, I just want to ask you one question. What advice would you give—well, let's assume that this experience has happened to you, and one of your neighbors comes to you and says, "You know, my employer wants me to volunteer to take some genetic test for some study that is being done."

Would you advise your neighbor to go along with that study or not, based on what has happened to you?

Mr. ESCHER. Well, based on my experience, I would highly recommend that he doesn't do it. And it is just that you are empowering someone to find things out about you that you don't even know yourself. And that is very powerful information that they can obtain from genetics testing.

And you have no idea how much morals or how much goodness these people have in their heart as to what they are going to do with the information that they get. I mean, it could be used for good things. Like I say, if it is in the hands of professional medical people, it is a great discovery. It is a good thing.

But if you let that type of information get into the hands of the wrong people, it is a devastating experience. And I am not saying that Burlington Northern as a company is a bad company. What I am saying is that the people who were in the leadership of that company at that time made some very poor choices.

Chairman ANDREWS. Thank you very much.

Mr. Kline?

Mr. KLINE. Thank you, Mr. Chairman.

I want to add my thanks to all the witnesses for being here. It is important and certainly moving testimony.

I think that there is a growing consensus among us that we should do what we can to block certainly intentional discrimination against an employee because of the genetic mapping. But I am concerned, and I know some of my colleagues are, that we not unintentionally ourselves do some damage when we pass this legislation.

So if I could turn to Mr. Fishman here briefly.

Keeping in mind that we are trying to have legislation that would prevent discrimination, you indicated, I think, in your written testimony that there would be with this legislation a de facto mandate or could be on a company to provide health coverage based on the genetic information.

Do I have that right? Could you kind of walk me through what you are trying to get at?

Mr. FISHMAN. I will do my best, Mr. Kline.

Just as the bill deals with contingent realities, I think we have to because the law of unintended consequences seems to multiply with legislation.

The proposed bill, for example, does not include language akin to that in executive order 13145. I think that says nothing in this order shall require specific benefits for any employee under a federal health program. So there is nothing in this bill which exempts employers from being compelled to provide coverage for any genetic ailment.

There are already suits which have under current law compelled employers to provide specific coverages for current ailments or current cures. As a result, employers face the specter of being sued to provide such coverage. And this bill provides a platform for doing so.

The coalition strongly believes that in this point, President Clinton was right in making clear that the limits of the executive order, and this law should have the same limit. This law should make clear that nothing in this bill shall be construed to required that specific benefits be provided for any employee or dependent under any insurance program, nor could any employer be sued for failing to provide a particular form of coverage.

Mr. KLINE. Okay, thank you very much for that amplification.

I am prepared to yield back in just a minute. But before I do that, I should make sure that I extend the thanks of Minnesota to Ms. Pearson and IBM for being a major employer in our state.

And just a comment. I think we need to be careful here. IBM has imposed a self-imposed limitation on how they use genetic information and so, perhaps may not be subject to some of the lawsuits which we might be concerned with when we pass legislation. And I hope as we work together as a subcommittee and a committee that we are careful to protect against discrimination and not open new pathways to litigation.

With that, Mr. Chairman, I yield back.

Chairman ANDREWS. Thank you, Mr. Kline.

Mr. Hare?

Mr. HARE. Thank you, Mr. Chairman.

Coming from a labor background, I am acutely concerned about any discrimination in the workplace, whether it is age-, race- or gender-specific. And today we are presented with an issue appropriate to our time and the amazing scientific and technological advancements that we have made as a society: discrimination based on our genetics.

We find ourselves presented with that age-old question regarding the fine line between scientific advancement and practice in our lives. What do we plan to do with the knowledge that we have? And do we use our advancement for good, finding cures for once incurable diseases or making one more comfortable in the workplace? Or do we use our knowledge in ways to discriminate and differentiate the value between people? When do we overstep that line and interfere with the natural world?

As Ms. Pearson states in her testimony, we legislate based on hindsight. I would like to go further in that and argue that we incorporate a bit of preemption in the process as well.

Look at issues such as affirmative action, limits on damages in jury cases, speed limits on our highways, and worker compensation laws, among other issues. All of these were established because of the potential for harm or because discrimination or harmful behavior existed. They are the results of preemption.

In case an event should occur, these laws exist to protect individuals. The value of our laws and how we are able to analyze them for improvement if loopholes are found and have the potential to be harmful or have, in the case studies presented today, proven to hurt people that the laws are trying to protect, well, then we must fix them.

And, of course, we cannot preempt everything. But when we have discovered instances where our laws are not working, it seems to me it is our obligation to amend them, especially as we approach a more scientifically evolved society.

There is a great risk involved in the advancement of our knowledge. And we must be aware of the potential for discrimination.

I just have two questions, maybe one for the panel and one specifically for Mr. Fishman.

For the panel, do you see other ways to protect employees from genetic discrimination that GINA does not address? And how can the protections outlined in the bill be stronger or more effective, would be my first question.

And if I could, Mr. Fishman, while I appreciate your arguments about access to one's genetic information being used to create employer-provided wellness programs or prevent exposure to harmful

working conditions, my question is, where do we draw the line? I believe this puts us on a very slippery slope. If we allow employers access to our genetic information for any reason, what prevents them from using it to discriminate as they did against Mr. Escher?

And let me just say, Mr. Escher, I am incredibly appalled by what happened to you. And I apologize for that. That never should have happened, and today no worker should be subjected to that.

Mr. FISHMAN. Well, while the panel is pondering the answer to your first question, perhaps I can respond to your one to me.

It is my understanding that legislation in its highest hopes cannot prevent. We have laws against bank robbery, but they don't prevent the bank robbers. We should have a law that prevents the nonconsensual disclosure of genetic information or the use of such information in employment decisions. That is what this law should be.

Can we prevent an abuse? Well, I wish you guys could figure out a way to do it. But so far it hasn't happened. But I have no problem and my coalition has no problem with a law directed at punishing the misuse and abuse and the incorrect use of genetic information. We are at one on that.

Ms. ROTHENBERG. I don't think there is any magic bullet in the world for people to respect one another. And we can pass all the laws we want, and that doesn't necessarily mean that people will stigmatize and figure out ways to hurt one another.

That said, I think we have to put in perspective that this debate has been going on for a long time. And we are tweaking now things that are—there have been some concerns expressed about record-keeping and some levels of damages.

But 12 years ago, 13 years ago when we were first trying to craft a proposal, it didn't look like this. It was significantly stronger, at least from the perspective of many. And this has been years and years and years of compromise where we are really sitting at a table where most people and most people on both sides are applauding it as at least making, I would argue, a very significant social policy statement that we might have not been able to do 20 years ago.

But we have seen this progression to the point where we can all say that we are not going to tolerate misuse of information. I would personally be making this stronger. Some of that is in the testimony. But I have a sense of there really being a consensus of taking that statement collectively and saying we have to give it a try.

And so, I think rather than tinker with how we could either make sure we don't have a frivolous lawsuit on the one side because that is also fear where there is no justification in fact for that in this context or on the other side that, you know, there is going to be not enough protections. It is a good start.

Chairman ANDREWS. The gentleman's time is expired.

Do either Ms. Pearson or Mr. Escher want to briefly respond to the question to the panel?

Thank you very much, Mr. Hare.

Dr. BOUSTANY?

Mr. BOUSTANY. Thank you, Mr. Chairman.

Ms. Pearson, I want to applaud IBM and your efforts in taking the lead on this issue. And I certainly appreciate your testimony

and welcome any suggestions you might have as we go forward with the legislation.

I have read in your testimony that the definition of genetic information may be defined over-broadly. And do you have any thoughts on how we might pare that down? And what are the consequences of an over-broad definition or over-inclusive definition?

Ms. PEARSON. Well, I think this is one of the core issues. And we, for example, in setting our own policy, we did a very simple thing because we ourselves were not sure how to define it. And we didn't want to kind of go down a road and then have it be legislated in a different way. And we added the word "genetics" to our equal employment opportunity policy alongside the other fundamental attributes that define us all as people, so gender, race, et cetera. And we left it to see how operationally, you know, practically, things would work.

In terms of the legislation, I don't have a specific suggestion other than to say that from an employer context we want to be very careful in how we manage data. I have been involved in managing data and information policy for a decade now. And operationally when you say let's collect data and apply certain policies to it, it is very important that we know what the data is that we are talking about.

And the water-cooler exception, for example, that was mentioned earlier by one of the members is very important because if you do inadvertently come into contact with information, even if you are not looking for it, you need to not be held to a standard here that is higher than if you are consciously seeking or arranging access to such information by the provision of health insurance coverage. Then it is absolutely relevant and worthy that we be held to a standard for managing that kind of data and managing carefully.

So I think it is clarity between that kind of information that is coming into your possession by virtue of arranging for employment or health insurance coverage versus water cooler or a kind of casual conversation sort of thing. Like in the workplace, you could mention to somebody that your mother has breast cancer, therefore the chances are higher, that sort of thing, which makes it, frankly, an operational challenge to figure out how do you actually manage to that. Those are the kinds of issues.

Mr. BOUSTANY. I thank you.

Dean Rothenberg, I want to look at the issue of job relevance. In your testimony you stated that an employer should be prohibited from requesting or requiring collection of genetic information unless it is relevant to the job. And I don't read that in the bill that we have as allowing for this sort of information.

So do you support a provision of that nature to be added into this bill? And could you comment on that?

Ms. ROTHENBERG. Yes, I thought Congresswoman Slaughter read some language with respect to that earlier on that actually did address that provision. Am I correct? Yes, okay. So there is some discussion about it.

When we made that recommendation over 10 years ago, I remember asking the scientists at the time was there actually anything that they knew about that would actually meet that. And at

the time, there really wasn't. So there could be in the future, and you would want to hold that.

Again, there should always be consent of the individual because an employee might decide I would rather walk away from a job than get information. And they should be given that risk benefit to be able to make individually. So I would never support a situation where any sort of testing is done under that rationale without there being some discussion and the employee's authorization.

Mr. BOUSTANY. Yes, and I would submit to you that there is a large gap between a genetic test and job relevancy. I am not aware of any—

Ms. ROTHENBERG. Right. And it is not only a test, it is information.

Mr. BOUSTANY. Right.

Ms. ROTHENBERG. So you might have information about someone's family history and there is no test. Three generations of people working in a mine, for example, all that develop some sort of disease. There might be some assumptions made about that, but there might not be any sort of test relevant or developed yet.

Mr. BOUSTANY. I would also say I am glad to hear that you mentioned the balance between the fear of having tests done and the other fear generated by a rash of frivolous lawsuits. And I think that is something we really need to keep in mind as we go forward in this.

Ms. ROTHENBERG. Well, one is, though, having an impact on your investment in the genome. So I think, as Congress, as a matter of social policy, for whatever reason, you don't want that paralyzing you.

Mr. BOUSTANY. Right, I understand that. But I think the other fear could also have a paralyzing effect as well.

Ms. ROTHENBERG. Okay. We haven't seen it in the states. We have not seen it. So if, in fact, we have 34 states in the employment context and 41 plus in the insurance context, I don't know why we are not. I mean, I have a whole bunch of assumptions about why we are not seeing the lawsuits, but I don't understand why all of a sudden they would jump up in this federal context when we haven't been seeing that much in the states.

Mr. BOUSTANY. I would just submit as we see more testing available and new tests coming out that this is something we clearly just need to watch.

Ms. ROTHENBERG. Yes.

Chairman ANDREWS. Thank you very much.

Ms. ROTHENBERG. I understand.

Chairman ANDREWS. Ms. Biggert, I am sure that you would like to participate in this discussion again. Thank you for being with us today and for your earlier testimony.

Mrs. BIGGERT. Thank you very much, Mr. Chairman, for allowing me to participate.

I have two witnesses I wanted to ask questions, and first is Dean Rothenberg.

I am going to go back to a question that one of our other members asked. In the definition portion of the legislation, the bill defines a family member as a child, including a child born to or

adopted by an individual. And some of the members raised concerns about that this legislation doesn't cover the unborn.

And it is my understanding that it does, because of the shield that, as I said before, that we have to keep in mind that genetic information would be used to prospectively discriminate and to attempt to project future risk. And since employment is not an issue and health coverage is already assured, a fetus is essentially shielded under its mother's current insurance.

And in practice, no provider of health coverage would improperly act against the unborn's interest, both because of the shield of the mother and the fact that after birth the child is fully protected.

Would you agree with that interpretation? And maybe you can't answer now.

Ms. ROTHENBERG. Could I just elaborate on—could we do a reality test on this issue? Perhaps it would help.

I was just trying to think this through a little bit when the question was asked earlier. And actually some of my earlier work is on prenatal genetic testing. And I think that as a reality most of the genetic testing going on in this country is being done on women when they are pregnant. That is the captive audience historically.

And in all my work in this area, my assumption has always been that if you had tested a woman while she was pregnant and there was some sort of genetic abnormality, it would reflect back into either the woman or the partner, the father, in this circumstance, that would have implications on their insurance.

The implications on employment are not with respect to the fetus. It is with respect to the family members associated with the fetus that would ultimately be born. So I think we are going down a slippery slope. I don't see the connection.

Mrs. BIGGERT. Well, I think that, to me, I guess it is a question of, you know, like a pro-life question.

Ms. ROTHENBERG. I don't see its relevance in the context of this legislation.

Mrs. BIGGERT. Because it really applies to the family, doesn't it, I mean, to the parents rather than to the coverage for insurance?

Ms. ROTHENBERG. Well, there isn't fetal insurance.

Mrs. BIGGERT. That is right.

Ms. ROTHENBERG. I mean, the fetus is sitting inside the woman.

Mrs. BIGGERT. Yes.

Ms. ROTHENBERG. So it goes together.

Mrs. BIGGERT. That is her coverage. Well, maybe if you could think about that. And if you have any ideas, I would love to get a written statement on that.

And I would ask unanimous consent to include the March of Dimes letter, which I think does address this somewhat.

Chairman ANDREWS. Without objection.

[The letter follows:]

OFFICE OF GOVERNMENT AFFAIRS,  
MARCH OF DIMES,  
*Washington, DC, January 19, 2007.*

Hon. OLYMPIA SNOWE, Hon. EDWARD KENNEDY, Hon. MIKE ENZI,  
*U.S. Senate, Washington, DC.*

DEAR SENATOR SNOWE, CHAIRMAN KENNEDY AND RANKING MEMBER ENZI: On behalf of the March of Dimes Foundation, I am writing to express our support for the soon to be introduced "Genetic Information Nondiscrimination Act of 2007." The

March of Dimes has a significant stake in the passage of this legislation. As you may know, at least 120,000 babies are born every year with birth defects. Children with severe birth defects may require expensive lifelong medical treatment. With the exciting progress of mapping the human genome, there is considerable apprehension that genetic information could be the basis for a new kind of discrimination.

The March of Dimes pioneered genetic services, including counseling and testing of individuals at risk, and led early efforts to provide genetic screening of populations at risk (particularly newborn screening). Because of our efforts, every state now provides newborn screening for a number of conditions that can be treated.

To fully reap the benefits of having deciphered the genetic code and determining patients' risk for certain conditions, they must be protected from discrimination in health insurance and employment. The Genetic Information Nondiscrimination Act provides these necessary protections by prohibiting health plans and insurers from using genetic information or services to make enrollment decisions or determine premiums.

With the progress of medical science, it would be a shame if parents were afraid to take advantage of the benefits of genetic testing and newborn screening because they feared retaliation from insurers. To give their children the protection they need to be screened without apprehension of discrimination, we look forward to working with you to ensure passage of this important legislation.

Sincerely,

MARINA L. WEISS, PH.D.,

*Senior Vice President, Public Policy and Government Affairs.*

Mrs. BIGGERT. And then I would also mention I think they know that the people are supporting this such as the president, you know, would be something to ask about.

And, Dr. Fishman, in the HHS Secretary's Advisory Committee on Genetic Health and Society 2005 report titled, "An Analysis of the Adequacy of Current Law in Protecting Against Genetic Discrimination in Health Insurance and Employment," it states that currently there are no federal laws that directly and comprehensively address the issues raised by the use of genetic information.

There are laws and court decisions that address part of these issues, but they leave substantial gaps in coverage and offer inconsistent safeguards at best.

Is it your position that there are no gaps in these federal laws?

Mr. FISHMAN. If I could just phrase it in a way that I can answer more accurately. It is our position that the historical record indicates that when these issues have been raised in a legal forum they have found adequate relief. Let me restate that again.

There has been a great deal of discussion, for example, as to whether this genetic discrimination will be covered under the—I think it is regarded as provision of the ADA. Now, no one in my profession ever gets rich by betting on judges or enforcement agencies. But the EEOC believes that the ADA offers protection.

And those handfuls—I am sorry—those fingerfuls of cases that have come up have found adequate relief under the current legal scheme. The EEOC does not appear to wish to change its views. No one appears to want to challenge it.

It is certainly true I think today, and we can say this with some certainty, that any employer who rejected an applicant or terminated an employee on the basis of a genetic marker would face certain enforcement both from the individual and from the EEOC and would, just as they would under the ADA, just as they would under the proposed bill—and if the historical is indicative, they would prevail.

Mrs. BIGGERT. Well, and then they go on further to say though that although individuals who encounter genetic discrimination cannot be said to lack any venues for relief under current law, many legal commentators agree that those avenues are uncertain and likely to lead to costly litigation and that current law does not adequately protect against genetic discrimination.

And, again, if I could submit this report?

Chairman ANDREWS. Without objection.\*

Chairman ANDREWS. The gentlewoman's time is expired.

Mrs. BIGGERT. Okay. Could I just ask one other question?

Chairman ANDREWS. Sure, absolutely.

Mrs. BIGGERT. Mr. Fishman was talking about President Clinton's Executive Order 13145. It was my understanding that that prohibited genetic discrimination against federal employees only.

Mr. FISHMAN. That is correct. My comment with respect to the executive order was the exception in it that provided that nothing in the executive order could be construed to require that the government provide specific coverage for specific ailments. And we wish that that same exception is articulated clearly in the pending legislation.

Mrs. BIGGERT. I just wanted to clarify that. Thank you.

Thank you, Mr. Chairman.

Mr. FISHMAN. Yes, ma'am.

Chairman ANDREWS. Thank you.

I would yield to my ranking member and friend for any final comments he may have.

Mr. KLINE. Thank you, Mr. Chairman.

Thanks again to the witnesses. And I yield back.

Chairman ANDREWS. Thank you.

I want to express my appreciation to the witnesses, the four witnesses this morning as well, Ms. Biggert, to you and Ms. Slaughter.

Again, at the outset of this hearing, the ranking member talked about his desire to build regular order as we move toward considering legislation. I share that goal. And I think we have taken a good step toward it this morning. We have had a lot of views expressed and questions raised. And we will continue to embrace and analyze those questions.

Again, thank you very much. The committee stands adjourned.

One more thing I have to do. Sorry. Without objection, all members will have 5 legislative days to submit additional materials for the hearing record.

Adjourned.

[Whereupon, at 12:45 p.m., the subcommittee was adjourned.]




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\*The May 2005 report, "An Analysis of the Adequacy of Current Law in Protecting Against Genetic Discrimination in Health Insurance and Employment," has been made a permanent part of this record and is archived at the Committee on Education and Labor. The report may also be viewed on the Internet at the following address: <http://www4.od.nih.gov/oba/SACGHA/reports/legal-analysis-May2005.pdf>