

PROTECTING WORKERS FROM GENETIC DISCRIMINATION

HEARING

BEFORE THE
SUBCOMMITTEE ON HEALTH,
EMPLOYMENT, LABOR AND PENSIONS
COMMITTEE ON
EDUCATION AND LABOR
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PROTECTING WORKERS FROM GENETIC DISCRIMINATION

Tuesday, January 30, 2007
U.S. House of Representatives
Subcommittee on Health, Employment, Labor and Pensions
Committee on Education and Labor
Washington, DC

The subcommittee met, pursuant to call, at 10:33 a.m., in room 2175, Rayburn House Office Building, Hon. Robert Andrews [chairman of the subcommittee] presiding.

Present: Representatives Andrews, Kildee, Tierney, Wu, Holt, Sanchez, Sestak, Loeb sack, Hare, Clarke, Courtney, Kline, McKeon, Marchant, Boustany, Hoekstra, Price, Foxx, and Walberg.

Staff present: Tylease Alli, Hearing Clerk; Jody Calemine, Labor Policy Deputy Director; Molly Carter, Legal Intern, Education; Carlos Fenwick, Policy Advisor for Subcommittee on Health, Employment, Labor and Pensions; Michael Gaffin, Staff Assistant, Labor; Lamont Ivey, Staff Assistant, Education; Brian Kennedy, General Counsel; Danielle Lee, Press/Outreach Assistant; Stephanie Moore, General Counsel; Joe Novotny, Chief Clerk; Lisette Partelow, Staff Assistant, Education; Rachel Racusen, Deputy Communications Director; Michele Varnhagen, Labor Policy Director; Michael Zola, Chief Investigative Counsel, Oversight; Mark Zuckerman, Staff Director; Robert Borden, General Counsel; Kathryn Bruns, Legislative Assistant; Steve Forde, Communications Director; Ed Gilroy, Director of Workforce Policy; Rob Gregg, Legislative Assistant; Jessica Gross, Deputy Press Secretary; Taylor Hansen, Legislative Assistant; Victor Klatt, Staff Director; Jim Paretto, Workforce Policy Counsel; Molly McLaughlin Salmi, Deputy Director of Workforce Policy; and Linda Stevens, Chief Clerk/Assistant to the General Counsel.

Chairman ANDREWS [presiding]. Ladies and gentlemen, the subcommittee will come to order.

We want to welcome everyone to the subcommittee, which has been rechristened the Health, Employment, Labor and Pensions Subcommittee. We are delighted that you are all here with us.

I want to say to my colleagues on the committee that I am humbled and honored to have the chance to work with you and lead the subcommittee. I hope to be worthy of your confidence and trust.

One of the very first things that I did when I was given this opportunity was to meet with my friend and colleague, Congressman Kline from Minnesota, who will serve as the Republican ranking

member. He and I have worked together on this committee as well as the Armed Services Committee. And I feel honored to have a chance to work with someone for whom I have so much respect.

And it is our mutual agenda that we will conduct the business of the subcommittee fairly and in a way that benefits the people that we all represent. There will certainly be times when we have vigorous disagreements, but I am committed and I know Congressman Kline is committed to the notion that we will pursue any disagreements in a civil, fair and responsible way. And where possible, we will find ways to work together.

I believe that this morning is a hearing that will focus on one of those ways where working together is very much within our reach. Our subcommittee is given responsibility for the issues that arise out of Americans in the workplace, whether it is their health insurance while they are working or retired, whether it is the nature of their employment relationship with their employer, the relationship between collective bargaining organizations and employers or the area of pension benefits for people, whether they are in a union or not, whether they are management, labor or what have you.

This is a large responsibility that we have been given. And I believe that when Speaker Pelosi took the gavel from the former chairman of this subcommittee, Mr. Boehner, and said that she wanted to proceed in the spirit of partnership rather than partisanship that today's hearing marks the first effort of what I hope will be many by our subcommittee to proceed in that spirit.

I believe there is an emerging bipartisan consensus addressing the issues that we will address this morning that we are so honored to have Chairwoman Slaughter and Congresswoman Biggert here to talk about.

I think there is a consensus in our country that when a person goes to apply for a job that he or she should not be denied the job because their family has a history of diabetes. I think there is an emerging consensus in the country that when a woman is working for a company that she shouldn't have to pay more for her health insurance than her peers because there is a family history of breast cancer in her family.

I think there is an emerging consensus in the country that no person should be told they are going to get fired if they don't agree to a genetic test. I think there is an emerging consensus in the country that if you have taken a genetic test and there is genetic information out there available to you, the information should only be given to people to whom you consent that it be given. And the tests should only be taken under circumstances in which you consent.

These principles were included in legislation which was identical to the legislation Ms. Slaughter and Ms. Biggert are talking about today, approved by the Senate 98-to-nothing. President Bush has strongly indicated that he is in support of these principles. So I think this is an excellent place for us to start our efforts to find ways that we can work together and improve the conditions of Americans in the workplace.

We are looking forward to the testimony this morning.

At this point, what I would like to do is to yield to my friend and colleague, the ranking member of the subcommittee, Mr. Kline.

Mr. KLINE. Thank you, Mr. Chairman.

Good morning to you all.

Let me start this morning by saying congratulations to you, Mr. Chairman. You and I have had the opportunity to work together on this committee and the Armed Services, as you pointed out, and I have found you always to be fair and forthright. And I am sure that that relationship will continue. I am looking forward to doing that work with you.

I do have to admit to you and to everyone that I would much prefer to be sitting in this chair than this chair. [Laughter.]

However, given that, I am happy to be sitting next to you. And I do think that there will be opportunities for us to work together and advance the agenda for the American people. In some cases and other cases you and I have agreed we were just going to agree to disagree.

I think that this morning's hearing is important. And I thank the chairman for moving forward with what I am sure will be the regular order of business in this subcommittee and the Committee on Education and Labor as a whole, as we examine the range of issues within our subcommittee, be they labor, health, pensions or otherwise.

And as the chairman has pointed out, there is a broad range of issues which we will be addressing. I hope that we will be mindful of the importance of the hearing and the markup processes and that we will begin and continue any legislative journey with a close contemplation of the facts.

Let me now turn to the issue before us today at this hearing: protecting workers from genetic discrimination. At the outset, I think the title of today's hearing embodies the proposition that all members of the subcommittee, as the chairman has pointed out, Republican or Democrat, would endorse, mainly that no employee should face discrimination on the basis of his or her genetic make-up, indeed, on any characteristic other than his or her qualifications for and the ability to do the job.

The idea that an employee might face adverse job consequences or risk their health insurance status because of the possibility that they might some day develop an illness is simply unacceptable. Nor should the fear of those consequences deter any individual from seeking the fullest and best medical screening and treatment available. I think these are points on which we can and will all agree.

I will say I am not sure that the case has been made that imposition of a broad new federal mandate on employers and insurers with respect to genetic discrimination is necessary. We will hear from witnesses today that many fear that their genetic information become public or may be used against them in some fashion. I won't call that fear unfounded, but I will say that before we consider broad reforms to our health insurance and employment laws, we need to determine whether there is a real problem here and if so, which is the best way to solve it.

Indeed, it bears noting that in the only recorded claim of genetic discrimination brought by the EEOC of which I am aware—and I think one of our witnesses today was, in fact, a plaintiff in that

case—the matter was settled quickly and efficiently by the EEOC, which recovered \$2.2 million for the plaintiffs under existing law. Again, that is the only documented case of alleged discrimination by an employer in the private sector for which we have details. But that was 5 years ago.

And since that time, to my knowledge, there has been no surge of lawsuits claiming that genetic discrimination by employers or insurers is a growing problem, despite the fact that our knowledge of the human genome—and it is truly miraculous what we have been able to discover—and our access to that information has grown exponentially in that time. Indeed, to the extent there was a concern with the actions of a single employer, some would say the system worked exactly the way it should have, again, under existing law.

If we assume for the sake of argument that some legislative action is necessary—and as I said, to my mind, the jury is still out on that question—the question then becomes what form this action should take. If there are legitimate concerns that genetic information is being misused or otherwise presents a risk, it would seem a matter of simple common sense to target any solution to the actual problem.

To go after a mosquito with a machine gun—and considering my past career in the Marine Corps, that is not necessarily a bad idea—but to go after a mosquito with a machine gun may not be the best way to solve the problem and almost surely will create others, some of which I guarantee you as sure as we are sitting here none of us have yet thought of.

In that light, some have suggested that with respect to health insurance and insurance coverage there may be greater consensus as to what legislative steps are helpful or necessary. If that is the case, a strong argument could be made for moving forward with insurance provisions on which there is agreement. We can then more closely examine issues relating more to employment and the broad use of genetic information in the workplace.

And then finally—and I must assure all of you what I promised the chairman, this will be the longest opening statement I will ever make as the ranking member. [Laughter.]

But finally, while today is an examination of the issue of genetic nondiscrimination generally, we will soon hear from two of our colleagues—and I am excited to see them here today, including our good friend and committee colleague, Ms. Biggert, who I think is going to join us later in the hearing—about one specific piece of legislation, the Genetic Information Nondiscrimination Act. I welcome their comments and a close examination of the proposed solution they have put forward.

I would say that as we approach this issue, I hope we are mindful that the committee process is intended to provide a forum for a close examination of a bill with the goal of perfecting the legislative product and improving whatever bill, if any, ultimately comes before all of us on the floor of the House. Too often we hear, “The devil is in the details.” On an issue as important as this one, it bears reminding that this committee is charged with making sure that the details are right.

I opened my comments by expressing my admiration for our chairman. And I would close by saying the same.

Rob, I look forward to working with you and the members of this committee. And I yield back.

**Prepared Statement of Hon. John Kline, Senior Republican Member,
Subcommittee on Health, Employment, Labor and Pensions**

Good Morning. Let me first say welcome, and congratulations, to my friend and the new chairman of our Subcommittee, Rob Andrews of New Jersey. I had the distinct pleasure of working with Mr. Andrews throughout the years I've been on this Committee, and although we may disagree on the substance of an issue, I've always known him to be fair, courteous, open-minded, and one of the most dedicated members of our Committee. While I would of course prefer to be sitting in his seat this morning, I know and trust that as we convene today's first hearing of the new Health, Employment, Labor, and Pensions Subcommittee, that his fairness and open-mindedness will continue on this leg of the journey.

This morning's hearing is an important one, and I thank the chairman for beginning today what I hope will be the "regular order" of business in our Subcommittee and the Committee on Education and Labor as a whole. As we examine the range of issues within our Subcommittee—be they labor, health, pensions, or otherwise—I hope that we will be mindful of the importance of the hearing and markup processes, and that we will begin and continue any legislative journey with a close contemplation of the facts.

Let me turn now to the issue before us at today's hearing, "Protecting Workers from Genetic Discrimination."

At the outset, I think the title of today's hearing embodies a proposition that all members of the Subcommittee—Republican or Democrat—would endorse. Namely, that no employee should face discrimination on the basis of his or her genetic make-up—or indeed, on any characteristic other than his or her qualifications for and ability to do the job. The idea that an employee might face adverse job consequences or risk their health insurance status because of the possibility that they might someday develop an illness is simply unacceptable. Nor should the fear of those consequences deter any individual from seeking the fullest and best medical screening and treatment available. I think these are points on which we would all agree.

I will say, I am not sure that the case has been made that imposition of a broad new federal mandate on employers and insurers with respect to genetic discrimination is necessary. We'll hear from witnesses today that many "fear" that their genetic information may become public, or may be used against them in some fashion. I won't call that fear unfounded—but I will say that before we consider broad reform to our health insurance and employment laws, we need to determine whether there is a real problem here, and if so, which way is best to solve it.

Indeed, it bears noting that in the only recorded claim of genetic discrimination brought by the EEOC of which I am aware—and I think one of our witnesses today was in fact a plaintiff in that case—the matter was settled quickly and efficiently by the EEOC, which recovered \$2.2 million dollars for the plaintiffs under existing law. Again, that is the only documented case of alleged discrimination by an employer in the private sector for which we have details—but that was five years ago, and since that time, to my knowledge, there has been no surge of lawsuits claiming that genetic discrimination by employers or insurers is a growing problem, despite the fact that our knowledge of the human genome, and our access to that information, has grown exponentially in that time. Indeed, to the extent there was a concern with the actions of a single employer, some would say the system worked exactly the way it should have—again, under existing law.

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In that light, some have suggested that with respect to health insurance and insurance coverage, there may be greater consensus as to what legislative steps are helpful or necessary. If that is the case, a strong argument can be made for moving forward with insurance provisions on which there is agreement. We can then more

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I began my remarks this morning by commending the Chairman for starting the process of “regular order” on this issue—I hope that this process continues, and that to the extent we move on to consider legislation, we are given the opportunity to examine it thoroughly and to amend or improve it in a thoughtful and deliberate matter. To simply pass a bill along, or to succumb to pressure by any party to do so—does neither our colleagues nor this institution a service.

With that, I welcome our witnesses this morning, and yield back my time.

Chairman ANDREWS. John, thank you very much for the compliment.

Two items: Pursuant to the rules, other members of the committee are welcome to make opening statements, without objection, will be considered in the record. Secondly, pursuant to the full committee rules, which are incorporated by reference in the subcommittee, members will be recognized for questioning in order of seniority for those present at the gavel. Thereafter, members will be recognized in order of appearance at the hearing.

[The statement of Mr. Hare follows:]

Prepared Statement of Hon. Phil Hare, a Representative in Congress From the State of Illinois

Coming from a labor background, I am acutely concerned about any discrimination in the workplace, whether it is age, race or gendered specific. Today we are presented with an issue appropriate to our time and the amazing scientific and technological advancements 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? Do we use our advancements for good, i.e. 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 than that and argue we incorporate a bit of preemption in that 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 many other issues. All of these were established because of the potential for harm or because discrimination or harmful behavior existed. They are the result of preemption—in case an event should occur, these laws exist to protect individuals.

The value of our laws rests in 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 the people our laws are trying to protect, well then we must fix them. Of course we cannot preempt everything but when we have discovered instances where our laws are not working, it is our obligation to amend them, especially as we approach a more scientifically involved society. There is great risk involved in the advancement of our knowledge and we must be aware of the potential for discrimination.

Questions for the panel

- Addressed to the entire panel: Are there other ways to protect employees from genetic discrimination that GINA does not address? How can the protections outlined in the bill be stronger or more effective?
- Mr. Fishman, while I appreciate your argument 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 you draw the line? I believe this puts us on a slippery slope. If we allow employers access to our genetic information for any reason, what prevents them from using it to discriminate?

I want to now turn to our colleagues who have come to testify this morning. Let me commend them for taking a very difficult issue, for negotiating with all the different interests and conducting really an exhaustive and comprehensive process to produce a piece of legislation that I think is visionary but also very carefully balanced.

And I particularly want to say to Chairwoman Slaughter that her years of devotion to this cause, I am confident, are going to come to fruition very, very soon.

And with that, I would recognize the chairwoman of the Rules Committee, Ms. Slaughter.

STATEMENT OF HON. LOUISE McINTOSH SLAUGHTER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Ms. SLAUGHTER. It has been a while since I have testified before a committee.

Mr. Chairman, let me congratulate you as well on your chairmanship and say good morning to you, to Mr. Kline and all the other members of the committee.

On this committee we have 11 co-sponsors on this bill. And to all of you I am extremely grateful.

If there was ever a bipartisan bill, it is this one. It has at this moment almost precisely the same amount of Republican sponsors as it does Democrat sponsors and over the years has enjoyed the sponsorship of most of committee chair.

And I certainly want to say how wonderful it has been to me, what a pleasure to work with Ms. Biggert. Both of us have toiled mightily in the field for 12 years to get this bill passed. We will not dwell at all on how far we could have been on this great science had we passed it years ago. But we are grateful this morning for the opportunity to bring it to you.

We think it is a bill whose time is long overdue. It is an important tool for science. And we know that it can make a major difference in people's lives.

I have a brief statement. I would like to put my complete statement into the record, if I may.

Chairman ANDREWS. Without objection.

Ms. SLAUGHTER. Thank you.

Let me thank you again. I hope our discussion this morning will lead to the timely and decisive package of strong genetic non-discrimination legislation that we have all been waiting for.

The Genetic Information Non-Discrimination Act, or GINA for short, is a culmination of a systemic bipartisan effort to prohibit

improper use of genetic information in the workforce and insurance decisions.

GINA prohibits group health plans and health insurance from denying coverage to a healthy individual or charging that person higher premiums based solely on the genetic predisposition to develop a disease sometime in the future. And we are talking about 30 or 40 years or perhaps never. It is probably the rankest form of discrimination that is practiced.

Furthermore, it bars employers from using an individual's genetic information when making hiring, firing, job placement or promotion decisions. In the 12 years since I first introduced the first version of genetic nondiscrimination legislation the need for it has grown exponentially. Scientific research has advanced so quickly that we cannot afford to wait any longer.

Since the sequencing of the human genome was completed in April of 2003, researchers have identified genetic markers for a variety of chronic health conditions and increased the potential for early treatment and prevention of numerous diseases. There are currently over 15,500 recognized genetic disorders that afflict 13 million Americans. In every one of us it is estimated—there is no perfect person. All of us are estimated to be genetically predisposed to between five and 50 serious disorders ourselves.

Fifteen percent of all cancers, for example, have an inherited susceptibility. Ten percent of adult chronic diseases like heart disease, diabetes—America's top killers—have a genetic component. Fortunately, there are already genetic tests for over 1,000 diseases, and hundreds more are undeveloped.

To give you an idea of the potential that exists, consider that genetic tests can tell a woman with a family history of breast cancer if she has the genetic mutation that can cause it long before any cancer develops. For these exciting scientific advances to continue and for the potential of this technology to be realized, we need to make genetic testing something that is commonplace rather than something that is feared. But sadly, ongoing genetic discrimination is making men and women ever less likely to be tested and to participate in clinical trials.

Significant examples of genetic discrimination already exist. Many know about the Burlington Northern Santa Fe Corporation case, which I believe Mr. Kline alluded to, and the case involving the Lawrence Livermore Laboratory. But you may not know about the North Carolina woman who was fired after genetic tests had revealed her risk for a lung disorder or the social worker who, despite outstanding performance reviews, was dismissed because her family had a history of Huntington's Disease.

These abuses along with others have only fed the growing public fear of genetic discrimination leading many Americans to forego genetic testing even if early detection of a particular genetic mutation could help avoid premature death.

In a recent 2006 Cogent research poll, 66 percent of respondents said they had concerns about how their genetic information would be stored and who would have access to it; 72 percent agreed the government should establish laws and regulations to protect the privacy of individuals' genetic information; 85 percent said that

without mending the current law, employers could use this information to discriminate.

Even health-care professionals are hesitant to make their own genetic information available. In one survey of genetic counselors, 108 out of 159 indicated they would not submit charges for a genetic test to the insurance companies primarily because they feared discrimination.

Genetic discrimination is wrong on two fronts. First, it is critical to remember that simply carrying a gene to a given genetic mutation almost never guarantees that one will fall ill. And the genetic flaw simply confers a level of risk upon the carrier.

Given that science cannot accurately predict when or whether a carrier will develop a disorder, it seems both criminal and illogical to allow this information to be used by health insurers or employers for discriminatory purposes. But what is more, if the individuals do not participate in the clinical trials, we will never be able to reap the real benefit to the genetic technology.

In a 2003 editorial, Dr. Francis Collins and James Watkins made the persuasive argument in favor of nondiscrimination legislation along these lines. They wrote, "Genetic discrimination has the potential to affect people's lives in terms of job insurance. But there is another dimension as well. It can slow the pace of scientific discovery that will yield crucial medical advances. Without the protections in place, the individuals who do agree to participate in studies will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find a better way in diagnosing, treating and preventing disease."

As a scientist myself, I cannot overstate the importance of having a truly representative sample size in clinical trials to ascertain valid research results.

Let me close by reiterating the broad support that this bill enjoys. It has substantial support from the health and science community. The Coalition for Genetic Fairness, which consists of over 140 organizations, has been outspoken in its support of GINA. I have here in my hands over 200 letters of support for GINA from a wide spectrum of health-related organizations. And as of today we have over 180 sponsors, both Democrats and Republicans, standing behind this bill.

The Senate has passed it twice with unanimous support. And even the White House has come out and supported genetic non-discrimination legislation. GINA will do more than stamp out a new form of discrimination.

It will help our country to be a leader in the field of scientific research that holds as much promise as any other in history. It is that important. And it will allow us to realize a tremendous potential of genetic research without jeopardizing one of the most fundamental privacies that can ever be imagined.

Mr. Chairman and Mr. Kline, once again let me thank you for the opportunity to speak at this hearing. And I look forward to working with you and all the members of the subcommittee as well as any other interested parties to enact this bill. I believe it is crucial that we do. Twelve years is too long to wait.

Thank you, Mr. Chairman.

[The statement of Ms. Slaughter follows:]

**Prepared Statement of Hon. Louise McIntosh Slaughter, a Representative
in Congress From the State of New York**

Mr. Chairman, I want to thank you for having this important hearing today and for inviting me to testify. I hope that our discussion will help lead to the timely and decisive passage of the strong genetic nondiscrimination legislation we have all been waiting for.

The Genetic Information Nondiscrimination Act, or GINA for short, is the culmination of a systematic, bipartisan effort to prohibit improper use of genetic information in workforce and insurance decisions.

GINA prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to develop a disease in the future. Furthermore, it bars employers from using an individual's genetic information when making hiring, firing, job placement or promotion decisions.

In the 12 years since I first introduced genetic nondiscrimination legislation, the need for it has grown exponentially. Scientific research has advanced so quickly that we cannot afford to wait any longer. What we need is a way to preserve Americans' health and protect our nation's scientific edge, all while defending the privacy of our citizens. I believe that this is what GINA will allow us to achieve.

We all watched with excitement when the first phase of the Human Genome project was successfully completed in April 2003, as scientists finished sequencing the human genome. From this first breakthrough, researchers have now identified genetic markers for a variety of chronic health conditions, and increased the potential for early treatment and prevention of numerous diseases.

There are over 15,500 recognized genetic disorders affecting 13 million Americans. No human being has a perfect set of genes. In fact, every one of us is estimated to be genetically predisposed to between 5 and 50 serious disorders. Fifteen percent of all cancers, for example, have an inherited susceptibility, and ten percent of adult chronic diseases (like heart disease and diabetes, America's top killers) have a genetic component.

Today, there are genetic tests for over 1000 diseases, and several hundred more are under development. To cite just one example: genetic tests can now tell a woman with a family history of breast cancer if she has the BRCA-1 mutation that can cause it—and do so long before the cancer develops.

But despite the scientific advances that are helping people prevent these diseases and diagnose them early, those who partake of this innovative technology are currently potential victims of genetic discrimination. And that is why we so desperately need to pass GINA: so that this area of dynamic research can move forward, and so that we can focus on improving health care in America without worrying that the knowledge we gain will be used to harm those it should be helping.

It is critical to remember that simply carrying a given genetic mutation almost never guarantees that one will fall ill. A genetic flaw simply confers a level of risk upon the carrier.

And given that scientists cannot accurately predict when or whether a carrier will develop a genetic disorder, it seems criminal to allow this information to be used by health insurers or employers for discriminatory purposes. An insurance bureaucrat or human resources professional would be as accurate with a dartboard as with a genetic test result in predicting who will get sick.

Critics say that this legislation is "a solution in search of a problem" and suggest that genetic discrimination is rare, if it even happens at all. Yet there are significant examples of genetic discrimination that we can point to already.

Many already know about the 2002 Burlington Northern Santa Fe Corporation case, where the company agreed to pay \$2.2 million to settle charges that it had tested employees without their knowledge for a genetic marker dubiously associated with carpal tunnel syndrome.

Or the reports in the early 1990s that Lawrence Livermore Laboratories was found to have for years been performing genetic tests on employees without their knowledge or consent.

There is also the fact that in the 1970s, many African Americans were denied jobs and insurance based on their carrier status for sickle cell anemia—again, despite the fact that a carrier lacks the two copies of a mutation necessary to get sick.

You have likely already heard about these examples. But you may not know about the North Carolina woman who was fired after a genetic test had revealed her risk for a lung disorder, even though she had begun the treatments that would keep her healthy.

Or the social worker whom, despite outstanding performance reviews, was fired because of her employer's fears about her family history of Huntington's disease.

Or the 1996 study that found a number of institutions, including health and life insurance companies, health care providers, adoption agencies, the military, and schools, that were reported to have engaged in genetic discrimination against asymptomatic individuals.

Such alleged discriminatory practices included an adoption agency refusing to allow a woman at risk for Huntington's disease to adopt a child, and an employer terminating an employee after they disclosed a risk of Huntington's disease.

A 2001 American Management Association survey of employer medical testing practices found that 1.3% of companies test new or current employees for sickle cell anemia, 0.4% test for Huntington's Disease, and 20.1% ask about family medical history. When asked if the results were used in hiring, reassigning, retaining or dismissing employees, 1% of employers indicated that sickle cell, 0.8% indicated that Huntington's, and 5.5% indicated that family history results were used.

These abuses have only fed the public fear of genetic discrimination, much to the detriment of America's public health and the future benefits of scientific research. Studies have shown that Americans are deciding to forgo genetic testing altogether because they fear discrimination, even if early detection of a particular genetic mutation may help avert premature morbidity and mortality.

A study conducted from 2001 to 2003 surveyed 86,859 adults about their willingness to undergo genetic testing. The results revealed that 40 percent felt genetic testing was not a good idea for fear that health insurance companies might deny or drop them from their insurance plan.

The Genetics and Public Policy Center at Johns Hopkins University conducted similar surveys. In 2002, 85 percent of those surveyed did not want employers to have access to their genetic information. By 2004, that number had risen to 92 percent. In 2002, 68 percent of those surveyed said their genetic information should be kept private from health insurers; by 2004, it had increased to 80 percent.

A 2003 study of 470 people with a family history of colorectal cancer showed that nearly half rated their level of concern about genetic discrimination as "high." Those individuals with high levels of concern indicated that they would be significantly less likely to consider meeting with a health care professional to discuss genetic testing, or to undergo testing, thus jeopardizing their ability to prevent this deadly disease.

In a recent 2006 Cogent Research poll, 66% of respondents said they had concerns about how their genetic information would be stored and who would have access. 65% said they were concerned about health insurance companies, and 54% were concerned with employers gaining unauthorized access. 72% agreed that the government should establish laws and regulations to protect the privacy of individuals' genetic information. And 85% said that without amending the law, employers would discriminate.

Fears about privacy do not just resonate with the public. Health care professionals are also hesitant to make their genetic information available. In one survey of genetic counselors, 108 out of 159 indicated that they would not submit charges for a genetic test to their insurance companies primarily because of the fear of discrimination. Twenty-five percent responded that they would use an alias to obtain a genetic test so as to reduce the risk of discrimination and maximize confidentiality. And, 60 percent indicated they would not share the information with a colleague because of the need for privacy and fear of job discrimination.

Mr. Chairman, Congressional action on genetic discrimination is necessary and long overdue. Genetic discrimination is unjustifiable in its own right. But what is more, if individuals do not participate in genetic studies, then we will never be able to realize the potential of this technology.

In a 2003 editorial, Dr. Francis Collins and James Watson made a persuasive argument for the need for legislative action. They said, and I quote: "Genetic discrimination has the potential to affect people's lives in terms of jobs and insurance, but there is another dimension as well: It can slow the pace of the scientific discovery that will yield crucial medical advances. * * * Without protections in place, individuals who do agree to participate [in studies] will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find better ways of diagnosing, treating, and preventing disease." End quote.

As a scientist myself, I cannot overstate the importance of having a truly representative sample size for research and in clinical trials to ascertain valid results.

GINA will do more than stamp out a new form of discrimination, as important as that is. It will also help us to resurrect our country's proud history of innovative,

advanced scientific and medical research, and to be a leader in this burgeoning field of genetic science.

Let me close by reiterating the broad support that this bill enjoys.

It has substantial support from the health and science community. The Coalition for Genetic Fairness, which consists of over 140 organizations, has been outspoken in their support for GINA. I have here in my hand over 200 letters of support for GINA from a wide spectrum of health-related organizations.

GINA has support from the American people, as is clear from the poll results I mentioned a few moments ago.

And GINA has support from a broad array of politicians. Here in the House of Representatives, the current legislation authored by Ms. Biggert, Ms. Eshoo, Mr. Walden, and I has over 175 cosponsors, both Democrats and Republicans. The Senate has passed this bill twice with unanimous support, and even the White House has come out in support of genetic nondiscrimination legislation.

Simply put, GINA provides the protections from genetic discrimination that Americans want, and this bill would allow genetic research to move forward so we can all live healthier lives.

Mr. Chairman, once again, let me thank you for holding this hearing today to shed light on this important issue. I look forward to working with you and all the Members of this Subcommittee, as well as any other interested parties, to enact H.R. 493, so that the future of genetic science will be something to embrace, instead of something to fear.

Chairman ANDREWS. Thank you, Chairwoman Slaughter, for your excellent presentation and your dedication to this cause.

We are honored to welcome home a member of our full committee, Ms. Biggert, who I am delighted will be joining us for the question period today when the second panel comes up.

And we thank you, Ms. Biggert, for your efforts to address the very valid concerns of the business community in making sure that this legislation is balanced. And we welcome and anticipate your testimony.

**STATEMENT OF HON. JUDY BIGGERT, A REPRESENTATIVE IN
CONGRESS FROM THE STATE OF ILLINOIS**

Mrs. BIGGERT. Thank you, Mr. Chairman. It is rather odd to be on this side of the table. I think I like being up there a little bit better. But I do thank you for holding this hearing and allowing me to participate.

And I also want to thank subcommittee members Mr. Boustany and Mr. Kildee, Mr. Hoekstra, Mr. Tierney and Mr. Marchant and Mr. Hare, who are among the 93 Republicans and the 82 Democrats co-sponsoring this bill. And last year we did have 244 sponsors of it. So I hope today's testimony will encourage other members of this subcommittee and the full committee to support this vital legislation.

Ms. Slaughter has eloquently addressed the public's fears of genetic discrimination and how it is a serious problem preventing Americans from utilizing genetic testing. I will focus my testimony on how technology can save lives and money and why I think these savings will be important, not just for businesses, but also for employees and their families. And finally, I want to address some of the concerns of the business community.

Genetic testing is the foundation of personalized and preventative medicine that focuses on catching diseases earlier when they are cheaper and easier to treat, tailoring treatment to each of our individual genetic makeups and preventing the onset of disease in the first place. For example, well, these genetic-based approaches

can save lives while having the added benefit of reducing health-care costs.

For example, many women who test positive for the Brach-1 mutation have up to an 85 percent chance of getting breast cancer. And many choose to have a mastectomy before the onset of the disease, which significantly reduces the chance that they will get breast cancer. At a cost of roughly \$12,000, this option dramatically reduces breast cancer treatment costs that can run into hundreds of thousands of dollars.

And even for women who have already developed breast cancer, genetic testing can lead to serious cost savings. For example, the breast cancer drug Arisa costs \$25,000 a year. But there is a simple genetic test that will predict whether or not this drug will effectively treat that cancer, thereby saving precious time and energy and money.

I chose the example of breast cancer to help to make the point that genetic testing can be deployed today to reduce health-care costs. But we are not just talking about tests for breast cancer. We are talking about 1,000 genetic tests that can predict whether an individual is more likely to get a disease.

With estimates showing each of us, as Ms. Slaughter noted, dozens of genetic mutations, this legislation is important to everyone. These widespread benefits have important implications to employers. Think about how vital this information would be to employer-provided wellness programs, which by their very nature focus on preventative measures. And think about how much employers could save on health care while keeping their employees healthy and productive.

Now, I know that this is at the heart of the debate within the employer community. It is the clash between those who see this legislation as a way to reduce health-care costs versus those who see it as a new opportunity for frivolous and costly lawsuits. So I would like to address the concerns of those employers by outlining what is required for an employer to be libel under this bill.

Genetic nondiscrimination isn't like race, age or sex discrimination. It is not apparent. You can't tell somebody's genetic makeup from looking at them. You have to search it out. In order for an employer to be libel under this act, he or she would have to intentionally or deliberately go looking for genetic information and then use it against an employee. An employer literally would have to go out of his or her way to discriminate.

I understand the concerns of the skeptics in the business community. My record in business speaks for itself. I am a supporter of business even by business communities' own standards. As the lead sponsor of this legislation, during the 109th Congress I met with them, discussed their concerns and worked with them. I think everyone involved worked in good faith on this issue. And these groups can trust that I will continue to give their concerns fair and honest consideration.

However, I do believe it is important to point out that the bill introduced in the 109th Congress, which is the same bill as today, is already a compromised bill that accommodates many of the concerns the business community had to the previous version of the

legislation, H.R. 1910 from the 108th Congress. So we made a lot of progress, I think, in moving this bill forward for their concerns.

Compared to H.R. 1910, today's bill is different in four important ways. The bill has a clear and precise definition of genetic information. It explicitly states that inadvertent acquisition of genetic information is not prohibited. It requires that claimants exhaust administrative procedures before seeking damages.

Under H.R. 1910, claimants could have gone directly to court rather than to the EEOC. And it caps damages under existing Title 7 levels, which vary by size of employer. And the previous bill had no damage caps. So I think that this legislation is much more friendly than H.R. 1910 from the 108th Congress.

Mr. Chairman, in passing this legislation we have a unique opportunity to improve the health and lives of the American people. But we will never unlock the great promise of the human genome project if Americans are too afraid to undergo genetic testing. I would like to give you just one short example.

I was doing a television interview. And the reporter asked me what would I like to talk about. And I said genetic information nondiscrimination. And she said I really want to hear this. She said that she had just had breast cancer. And her doctors told her that she should undergo genetic testing to see if she had the predisposition for ovarian cancer, which is in some cases a high predisposition. And she said to her doctor, "I can't have the test because I will lose my job."

So without the protections offered by H.R. 493 I think these fears will persist, research at NIH will slow and Americans and American businesses will never realize the benefits and savings of gene-based medicines. So it is time the House joins the Senate and the president in supporting this critical bill.

I thank you.

[The statement of Mrs. Biggert follows:]

**Prepared Statement of Hon. Judy Biggert, a Representative in Congress
From the State of Illinois**

Thank you, Mr. Chairman, for holding this very important hearing today and for allowing me to participate. I also want to thank Subcommittee Members Mr. Rush, Mr. Boustany, Mr. Kildee, Mr. Hoekstra, Mr. Tierney, Mr. Marchant, and Mr. Hare, who are among the 175 cosponsors—including 93 Republicans and 82 Democrats—of this bipartisan bill. I hope today's testimony will encourage other members of this Subcommittee and our colleagues on the full Education and Labor Committee to support this vital legislation.

Mrs. Slaughter has eloquently addressed the public's fear of genetic discrimination and how it is a serious problem preventing Americans from utilizing genetic testing to improve their own health and reduce healthcare costs. I will focus my testimony on how this technology can save lives and money and why I think these savings will be important—not just for businesses, but also for employees and their families. Finally, I want to address some of the concerns of the business community.

Genetic testing is the foundation of personalized and preventative medicine that focuses on:

1. Catching diseases earlier when they are cheaper and easier to treat;
2. Tailoring treatments to each of our individual genetic makeups; and
3. Preventing the onset of disease in the first place.

Along every step of the way, these genetics-based approaches can save lives while having the added benefit of reducing healthcare costs.

For example, many women who test positive for the BRCA1 mutation have up to an 85% chance of getting breast cancer. Many choose to have a prophylactic mastectomy before the onset of disease, which significantly reduces the chance they will

get breast cancer. At a cost of roughly \$12,000, this option dramatically reduces breast cancer treatment costs that can run into hundreds of thousands of dollars.

Even for women who already have developed breast cancer, genetic testing can lead to serious cost savings. For example, the breast cancer drug Iressa costs \$25,000 a year, but there is a simple genetic test that will predict whether or not this drug will be successful, thereby sparing false hope and saving precious time and money.

I chose the example of breast cancer to help make the point that genetic testing can be deployed today to reduce healthcare costs. But we're not just talking about tests for breast cancer. We're talking about a thousand genetic tests that predict whether an individual is more likely to get a disease. And we're not talking about just helping a few people. Estimates show that on average, each of us carries dozens of genetic defects that put us at risk.

These widespread benefits have important implications to employers. Think about how vital this information could be to employer-provided wellness programs, which by their very nature focus on preventative medicine. Think about how much employers could save on healthcare while keeping their employees healthy and productive.

Now I know that this is at the heart of the debate within the employer community. It's the clash between those who see this legislation as a way to reduce healthcare costs versus those who see it as a new opportunity for frivolous and costly lawsuits. So I just want to take a moment to address the concerns of those employers by outlining what is required for an employer to be liable under this bill.

Genetic nondiscrimination isn't like race, age, or sex discrimination * * * it's not apparent. You can't tell someone's genetic makeup from just looking at him or her—you have to dig, and you have to dig deep. In order for an employer to be liable under this act, he or she would have to intentionally and deliberately go looking for genetic information and then use it against an employee. An employer literally would have to go out of his way to discriminate and that would be a problem.

I understand the concerns of the skeptics in the business community. My record on business issues speaks for itself. I'm a supporter of business even by the business community's own standards. As the lead sponsor of this legislation during the 109th Congress, I met with them, discussed their concerns and worked with them.

I think that everyone involved worked in good faith on this issue and these groups can trust that I will continue to give their concerns fair and honest consideration. However, I do believe it is important to point out that the bill I introduced in the 109th Congress, which is the same as the bill we are considering today, is already a compromise bill that accommodates many of the concerns the business community expressed about the previous version of the legislation that was introduced in the 108th Congress, H.R. 1910.

Compared to H.R. 1910, the legislation that we consider today is different in four important ways. Our bill:

1. Has a clear and precise definition of genetic information;
2. Explicitly states that inadvertent acquisition of genetic information is not prohibited;
3. Requires that claimants first exhaust administrative state and federal procedures before seeking court damages or equitable relief; under H.R. 1910, claimants could have gone directly to court; and
4. Caps damages under existing Title VII standards, which include a small business threshold for coverage, and varying caps on damages depending on the size of the firm; H.R. 1910 had no damage caps.

As a result of these accommodations, this legislation is much more business friendly than H.R. 1910 from the 108th Congress. I would stress that I support these changes and they should be maintained.

Mr. Chairman, in passing this legislation, we have a unique opportunity to improve the health and lives of the American people. But we will never unlock the great promise of the Human Genome Project if Americans are too paranoid to undergo genetic testing. Without the protections offered by H.R. 493, these fears will persist, research at NIH will slow, and Americans and American businesses will never realize the benefits and savings of gene-based medicines.

It's time the House joined the Senate and the President in supporting this critical bill.

Thank you and I look forward to your questions.

Chairman ANDREWS. Thank you both very much for your testimony.

I wanted to pick up with Ms. Biggert's point, Ms. Slaughter, if I could, about her friend, the television reporter, who felt concerned about taking a genetic test for fear that the information would cause her to lose her job.

The other concern that I think you, Ms. Slaughter, mentioned very well is the chilling effect on genetic research that is taking place right now because so many Americans have the fear that Ms. Biggert just talked about, that if they take a genetic test, that the information will be shared with people that they don't want to have it and there will be consequences for them with their employment or their health insurance that they do not wish to have.

Make a prediction for us as to what you think would happen if we don't pass this legislation. What negative impact do you think it would have, failure to pass this legislation, on the evolution of genetic research?

Ms. SLAUGHTER. I think it has had a chilling effect already. Ms. Biggert and I have both talked about the numbers of people that have come to us as well as the number of physicians who have said to us we recommend to our patients not to have the test.

Let me make one point again. I want to make sure—this is terribly important. Not a single one of us in this room, not the president of any company or any corporation, not the CEO of any health insurer is immune from this. It affects every single human being alive. The idea to discriminate against some of them who have had a test is appallingly bad.

One wonders what would happen if we required all of the CEOs in these corporations to have their own genetic tests and let their board of directors and their stockholders find out what they might get in 30 or 40 years. And I would guarantee you that in very short order this bill would be passed. But scientists have already told us that people will not sign up for research projects and that people will not have the test—or if they are terrified in the case of ovarian or breast cancer, they will find a way to get the test and try to pay for it themselves and try to keep the information private.

It is an underground medical phenomenon that is going on. You only have to talk to a few people who have expressed the fear of what happened to them to understand the far-reaching aspects of this bill.

I will never forget one woman who had received nothing but glowing reports from her employers, one promotion after another as she was quickly rising to the top. And they discovered that her brother had a genetic disease that would not affect her because it was only in the males in the family. And nonetheless, she was fired. And then try to get another job somewhere after you have been let go because you are considered not to be healthy enough.

Chairman ANDREWS. And your bill would make that an unlawful employment practice?

Ms. SLAUGHTER. Yes.

Chairman ANDREWS. For every person in the country, irrespective of what state they live in?

Ms. SLAUGHTER. Absolutely.

But speaking of states, 30 states have already passed genetic discrimination. The difficulty is that we have so many corporations in

this country that cover 50 states. You can think of them momentarily in a minute.

Xerox, for example—let's say that you had, as a corporation head, you had to comply with 50 state bills and laws on genetic discrimination. You would beg for a federal law that everybody could comply with, know what they were dealing with and that you would not have to try to hire realms of lawyers to try to deal with the 50 states.

Chairman ANDREWS. We are not against hiring lawyers. I want to go on the record as correcting that right away. We are kind of for it. I speak for myself, but I want to be very clear about that.

Ms. Biggert, one of the concerns that was raised about in early discussions of the bill was what about an employer inadvertently acquiring genetic material. What does the underlying bill do in that case? If an employer inadvertently acquires genetic material, are they legally liable under your proposal?

Mrs. BIGGERT. No, in fact, there is an exception for that. And it is called the water cooler exception. And that is if, you know, somebody talks about it at the water cooler or wherever and they discover that there is that predisposition, now, they can't use that. But it has to be that they would intentionally discriminate against somebody. But that is a carve out for the bill.

Chairman ANDREWS. I know that another concern was the attraction of lawsuits, burdensome lawsuits. This bill imposes a requirement that people exhaust their administrative remedies. Isn't that correct?

Mrs. BIGGERT. Right.

Chairman ANDREWS. And if I read the bill correctly, in cases where the secretary of labor is deciding on penalties against a health insurer or an employer, the secretary of labor has the discretion to reduce penalties or to otherwise modify them. Is that also correct?

Mrs. BIGGERT. Yes. But the way that a suit would happen would be with the EEOC.

Chairman ANDREWS. Right.

Mrs. BIGGERT. That would be the administrative remedy that most people would pursue. And then there is a cap on the damages. And it is Title 7, which is the Civil Rights Act so that the damages both punitive and compensatory cannot exceed \$50,000 for an employer with 15 to 100 employees, \$100,000 for an employer with 100 to 200 employees and \$200,000 between 200 and 500 employees and \$300,000 for an employer with more than 500 employees. So even if you are looking at the Burlington case, which was settled for \$2.2 million, that probably wouldn't even reach that amount under this legislation.

Chairman ANDREWS. As Ms. Slaughter said, this—I am sorry.

Mrs. BIGGERT. That is okay. Yes. What we wanted to make sure is that there has to be some penalty because otherwise it might not be—you know, they wouldn't take it seriously. But we didn't want it to be onerous and to have the frivolous lawsuits or, you know, we didn't really want to create another lawsuit stream.

Chairman ANDREWS. As Ms. Slaughter said, my sense of the bill is the result of very careful compromise over a long period of time.

I am going to yield to Mr. Kline. Let me just say to the members I know that Ms. Slaughter and Ms. Biggert have other commitments. Anyone is welcome to ask any question they wish of the members. But to the extent that we can get the members on their way and get to the expert panel, we should. But, please, if you have questions for the members, please feel free. And I would start with my friend, Mr. Kline.

Mr. KLINE. Thank you, Mr. Chairman.

And thank you, ladies, for being here. This is a very unusual position, especially with a very powerful chairwoman of the Rules Committee to be sitting there.

Ms. SLAUGHTER. It is a pleasure to be here. I have waited a long time for this.

Mr. KLINE. I know you have. And I want to commend both of you for the energy and passion that you have put into this legislation.

Ms. SLAUGHTER. It has been a pleasure working with Ms. Biggert.

Mr. KLINE. Well, perhaps I should take advantage of this opportunity and ask the chairwoman could we expect when this comes to the floor that we are going to have some amendments and some, you know, regular order and open rule.

Ms. SLAUGHTER. We don't prejudge any—

Mr. KLINE. I see.

Ms. SLAUGHTER. We not only have an open mind, we are pledged that once we get by this for 2006 six that you are going to see wonders performed.

Mr. KLINE. I am eager to get past the six for 2006. Thank you, Madam Chairwoman.

Let me ask you this. An interesting issue just popped up during the chairman's questions. And that is the issue of preemption here. Are you saying that this legislation would provide a common law, common standard, if you will, nationwide and would preempt the 50 states? Or do we—

Ms. SLAUGHTER. That certainly is my hope.

Mr. KLINE. Okay. I am not sure that the language—

Ms. SLAUGHTER. Otherwise—

Mr. KLINE.—in your bill does that. So I am—

Ms. SLAUGHTER. Unless that happens, you are really going to be left with standards in various states. And, you know, it shouldn't be the luck of the draw where you are born, what state you are in whether you are going to be protected from discrimination or not. Discrimination is absolutely a federal issue.

Mr. KLINE. Thank you.

And, Ms. Biggert, just to beat this horse one more time on this issue of intentional abuse versus accidental, I want to be clear that this language makes it clear that an employer who intentionally gets genetic information and intentionally discriminates against a potential or current employee because of that—that is what this legislation is aimed at, not accidental or unintentional misfiling kind of thing. Is that correct?

Mrs. BIGGERT. That is correct.

Mr. KLINE. Okay. Okay. Thank you. And then I will yield back. I think Mr. Boustany would like to be recognized.

Chairman ANDREWS. Do you want to yield your time to Mr. Boustany, the remaining time? Or does he want the full 5 minutes?

Mr. KLINE. No.

Chairman ANDREWS. Okay. Mr. Kildee is next for us.

Mr. KILDEE. Just a statement. I want to thank my two colleagues for pushing legislation to make sure that the law catches up with the emerging research that can be a boon to people but also can be used as a burden on those people. And the law should always catch up with the emerging research and technology. And you are right on top of things. And I just want to thank both of you.

Ms. SLAUGHTER. Thank you, Mr. Kildee.

And let us make it clear again, both of us, that the entire scientific community in the United States—I haven't been through it to find every one of them, but everybody you know and respect and admire is in one of these letters. And they have been crying out for this bill for years because they really believe that there is a new way, particularly in the case of doctors, that they can provide health care. And I believe that that is the case.

Chairman ANDREWS. Mr. Kildee, are you yielding back?

Mr. KILDEE. I yield back.

Chairman ANDREWS. Thank you very much.

Dr. Boustany, I understand, wants to ask a question. He is recognized for 5 minutes.

Mr. BOUSTANY. Thank you, Mr. Chairman.

I am proud to co-sponsor this bill with you all. And I want to commend you on your diligence and persistence in moving this. And I am happy to see that this is actually going through the legislative process now.

You know, the mapping of the human genome, science of genetics, I believe, represent one of the most important advances in medicine. And it is going to profoundly effect the way medicine is practiced in the future. And I think this debate highlights an inherent basic problem we have in our health-care system. And I want to highlight that.

And that is we currently have the interposition of managed care entities, insurance companies, the employers as well as governmental entities and bodies between the doctor and the patient. And that is a problem because a lot of very sensitive information flows through that system that can be abused or leaked out in some fashion that could be harmful to the patient. And I think it is important that we look at that broad picture as we approach this legislation.

And I am going to ask a question now. You don't need to answer this now, but I think it is a question that we as a committee need to entertain as we go forward.

Will this bill, if passed, push employers and insurance companies and other entities that utilize sensitive health information out of that business for fear of lawsuits or as a result of lawsuits so that we eventually get to a point where we have just the doctor and the patient now dealing with sensitive information and these other entities simply dealing with actuarial data and statistical information only?

And so, that is a question I think we need to entertain as we go forward in this debate.

Again, I want to thank you all. I am looking forward to working with you on the bill.

Ms. SLAUGHTER. We appreciate your co-sponsorship.

Mr. BOUSTANY. I yield back.

Chairman ANDREWS. Thank you very much.

Mr. Holt is recognized for 5 minutes.

Mr. HOLT. Thank you, Chairman Andrews. And I am delighted to call you that. And I thank you for bringing this up as the first hearing of this subcommittee.

Ms. Slaughter and Ms. Biggert, you have been persistent in this, and I thank you for that.

And I would like to actually ask you something that maybe you are better able to answer than the witnesses who will be coming, which has to do with why a bill that makes such eminent good sense has been so slow to move. I mean, this is something that we know existing protections are minimal.

We know this is consistent with not only the Health Insurance Portability Act and with the Americans with Disabilities Act and any number of other principled pieces of legislation, principled pieces of law out there. But clearly, there has been something standing in the way. And maybe things would change if we required CEOs of companies to take and disclose the results of intelligence tests to the public.

But something is standing in the way. And I am wondering if you could characterize what it is that we have been up against here and why it is at this late date we haven't done it yet.

Mrs. BIGGERT. Well, I think, first of all, is the fear of frivolous lawsuits. But it is more than that. I think people have a fear of getting the test because of what might happen. And I think Mr. Kline characterized it. There hasn't been the problem, so there doesn't need to be a solution.

But the problem is that because the people fear doing this nobody is getting these tests, so nobody is finding out what they might be predisposed to. Nobody is in the trials so we are not finding the cure for the diseases that we should be able to. And so, it is like circular, that it is going round and round.

There is no testing, so there is no problems of discrimination. I think that people fear the unknown. In fact, when I started out asking people, you know, would they want to get a genetic test. And so many people said I just don't want to know. I am afraid to find out even.

Even though you said this has been going on for a long time, it really hasn't until recently. And we see all these cases on television, you know, with the people getting, you know, genetic tests. And it has been relegated to the criminal side of this. And now we are in this civil—and the technology has increased so. And technology usually outpaces us, you know, so that we have to catch up with it.

And I think this is a case where we haven't caught up yet with our rules and regulations and how to deal with this. And I think it has taken that time and working with the business community and with—the insurers, you know, have reached the conclusion that this is—you know, they are for it. And now we just need to

bring the employers along. And I think working with them over the past couple of years has helped.

Ms. SLAUGHTER. I signed an oath this morning that I would do nothing here but tell the truth, so I can't actually prove why we have never done anything about it. So let me restate this. We have this science. And this is made available to anybody. And we could have had it 12 years ago.

And I think the Senate first passed it maybe 6 years ago. But, you know, it doesn't matter at all unless we have two houses and the president's signature. We could provide health care in a new way. We could save enormous amounts of money. But we could save enormous amounts of pain and anguish. And there are no losers here.

If there were, we wouldn't have total bipartisan sponsorship on this bill. But I remember as a child when they first started doing organ transplants. And the idea was if God wanted you to have a good liver, he surely would have given you one. But we have to move past that mindset and take advantage of the wonderful new technology that can make us all better.

And, you know, just think about it. Every member in your family, everyone you know and love could be discriminated against by this law easily. I mean, by lack of this.

Mrs. BIGGERT. Let me just say, too, that it is not the business community so much. It is more the associations that have the fears. I mean, there are a lot of businesses doing this on their own. And you are going to hear from one today. So we have to kind of separate out that the whole community has problems with this because I don't think that that is true.

Chairman ANDREWS. Gentleman's time is expired.

Mr. HOLT. I thank the witnesses. I yield back.

Chairman ANDREWS. Thank you.

Dr. Price, you are recognized for 5 minutes.

Mr. PRICE. Thank you, Mr. Chairman. I want to add my voice to those individuals congratulating you on your chairmanship here. I look forward to working with you on this committee. I think this is an exciting committee. It is where the nuts and bolts of the larger committee will be. And I appreciate the opportunity to serve with you.

I want to commend each of you as well for the work that you have done in bringing this issue forward. As a physician, though, I would be remiss if I didn't say that science is way ahead of politics virtually all the time.

Ms. SLAUGHTER. We need to catch up.

Mr. PRICE. Well, I would respectfully suggest that it is impossible for us to catch up. We can work hard, and we can try to get there, but as soon as this bill is passed, science will be beyond us.

But I did have a couple specific questions. I want to commend you for many items, not the least of which is the importance of clinical trials and making certain that folks aren't concerned or anxious or reticent about participating in clinical trials. And I know that you say that this bill protects individuals in clinical trials. And I should have spent more time reviewing it, but I can't find that specifically or explicitly stated.

If you or your staff could be able to point me in that direction, that would be helpful. You may know.

Ms. SLAUGHTER. Yes, that people will not sign up for trials?

Mr. PRICE. No, where in the bill it specifically says that—

Ms. SLAUGHTER. Well, all the bill does is protects you from discrimination from your employer and insurance company, which is really what the fear is to keep people out of the clinical trials. They don't want to be a part of that if their name is going to be bandied about and their employer says I had better be worried here because Joan is over in that test. There may be something wrong with her that I want to know about.

Mr. PRICE. So it implicitly states that. Would you be willing—

Ms. SLAUGHTER. As far as we know, those are the two fears, Doctor, that they will be discriminated against in both their employment and insurance.

Mr. PRICE. Would you be willing to consider some language that explicitly states that? I don't have any language, but if—

Ms. SLAUGHTER. That a person who agrees to undergo a clinical trial?

Mr. PRICE. Clinical trial.

Ms. SLAUGHTER. I can tell you if they don't have the protections from discrimination no matter what, I don't think they would go into the trial.

Mr. PRICE. Well, maybe we can talk about that.

Ms. SLAUGHTER. All right, certainly, be glad to.

Mr. PRICE. And my good friend, Mr. Kline, talks about the—he is gone, I see. But he talks about the reason that this may not be coming to pass to date is because we haven't provided for intelligence tests for CEOs. I would respectfully suggest that if we provide an intelligence tests for members of Congress, we might get closer to the answer as opposed to the other.

Ms. SLAUGHTER. Do you know I have been obsessed with the idea of a national I.Q. test? I don't know any way we could ever do it, but I bet it would really make us think. [Laughter.]

Mr. PRICE. There you go.

I have a couple very specific questions. And again, it may be that your staff may be able to help me more. But I know that it is not oftentimes felt by people, but there are insurance companies who are indeed interested in the health of their insured.

Ms. SLAUGHTER. Of course.

Mr. PRICE. And in the bill—

Ms. SLAUGHTER. I hope they all—

Mr. PRICE.—in multiple places throughout the bill it states that an insurance company may not require explicitly a genetic test in spite of the fact that, as you say, genetic tests oftentimes can reveal clinical situations that would benefit from treatment, preventive sorts of treatment.

Is there a rationale for that?

Ms. SLAUGHTER. I think there are some exceptions in here. For example, if they are employed in the kind of job—let me see.

Mr. PRICE. Maybe it is just a—

Ms. SLAUGHTER. Employment agencies, labor organizations can require genetic information in the following circumstances: when they offer a health service program; when the employee provides

written authorization; when the information is used to monitor the biological effects of toxic substances in the work place but only if the employer provides written notice of genetic monitoring, the employee provides written authorization and genetic monitoring is required by federal or state law, the employee is informed of the monitoring results, the monitoring is conducted in compliance with federal genetic monitoring regulations and the identity of specific employees is not disclosed.

Mr. PRICE. Maybe we can talk about that as well, as we go through this process.

Ms. SLAUGHTER. Sure, all right.

Mr. PRICE. And I appreciate the opportunity to have some input into that. I think it is important that we not limit the ability of an insurance company, for example, to highlight and recommend the types of tests or screening tests that they would see as appropriate for the insureds to assist in the health outcomes of the other treatments.

Ms. SLAUGHTER. As long as the health insurer recognizes her husband or his wife to be part of this as well—

Mr. PRICE. Absolutely, yes, without a doubt.

And then finally, I wonder if each of you might comment on, if an individual is let go from employment for a reason not related to genetic testing, who would have the burden of proof if the employee were then to bring a complaint forward? Is it the employer that would have the burden of proof to prove a negative? Or is it the employee that would have the burden of proof to prove that that, in fact, didn't occur or did occur?

Mrs. BIGGERT. If they go to the EEOC, which they would, exhaust the administrative law, usually when that happens, as I recall in having done this, is that the employee, you know, submits their charges to the EEOC and then the EEOC decides whether this case should go forward or not. So it really is the burden of the employee to bring that to the EEOC.

Mr. PRICE. To bring the case to prove the case?

Mrs. BIGGERT. Yes. And if then under that law if they—at least in terms of civil rights—if they are denied, then they can go to the courts after that.

Chairman ANDREWS. Yes, the gentleman's time is expired.

Mr. PRICE. Thank you so much, Mr. Chairman.

Chairman ANDREWS. Ms. Slaughter, did you want to answer the question?

Ms. SLAUGHTER. No, I think Ms. Biggert did a wonderful job.

Chairman ANDREWS. Okay.

The representative of one of the more dynamic legislatures in the world, the New York City Council, who is now our colleague, Congresswoman Clarke, is recognized for 5 minutes, alumnus of the New York City Council.

Ms. CLARKE. Thank you very much, Mr. Chair.

And to Representative Slaughter and Representative Biggert, thank you so much for bringing this legislation to light. I look forward to being a strident advocate on behalf of this legislation.

Mr. Chairman, there are constitutional issues relating to employers who use potential employees and genetic information as a basis for employment. It is my hope that this hearing today will bring

clarity to the hiring practices of people, and in particular, I am most concerned with this type of discrimination heavily affecting African-Americans who are purported to be genetically predisposed to sickle cell disease or to Jewish Americans who are predisposed to Tay-Sach's disease.

This predisposition, particularly with regard to sickle cell disease, does not guarantee that every African-American with the genetic signature will manifest the disease. And H.R. 493, the Genetic Information Nondiscrimination Act of 2007, also known as GINA, introduced by Representative Slaughter is an attempt to correct discriminatory practices using genetic information as a basis for the discrimination.

The human genome project produced detailed maps of 23 pairs of human chromosomes and sequenced 99 percent of the 3 billion nucleotidized bases that make up the human genome. The sequenced information should aid in the identification of genes' underlying disease raising hopes for genetic therapies to cure disease. But this scientific accomplishment is not without potential problems, potential abuse and potential misuse, which is why we are here today.

The ethical, social and legal implications of these technological advances have been the subject of significant scrutiny and concern. However, there have yet to be answers to the questions of how we legally protect our citizens from discrimination. If all the answers to all the questions were available, we wouldn't be here today.

Mr. Chairman, my constituents in the 11th District of New York, the borough of Brooklyn, suffer from an abnormally high unemployment rate. Throughout New York City, according to the 2004 study by the Community Service Society, "A Crisis of Black Male Unemployment and Joblessness in New York," the study finds that city-wide unemployment rates stood at 8.5 percent in 2003, but for many groups of New Yorkers it was considerably higher. It includes teens at 28.7 percent; young adults, 13.1 percent; blacks at 12.9 percent; Hispanics at 9.6 percent. And these concerns will be compounded as we move forward with such a technologically advanced society.

Should genetic information be able to flow seamlessly between employers and those that have the capacity to get this information out, citizens unknowingly could be prevented from being hired.

And so, today, Mr. Chair, I would like to submit my comments and the report for the record* and thank both of you for bringing this to light. Thank you very much, Mr. Chair.

[The statement of Ms. Clarke follows:]

**Prepared Statement of Hon. Yvette D. Clarke, a Representative in Congress
From the State of New York**

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*The February 2004 report, "A Crisis of Black Male Employment, Unemployment and Joblessness in New York City, 2003," 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://www.cssny.org/pubs/special/2004-02labormarket.pdf>

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- The citywide unemployment rate stood at 8.5 percent in 2003. But for many groups of New Yorkers it was considerably higher. That includes: teens, 28.7 percent; young adults, 13.1 percent; Blacks, 12.9 percent; Hispanics, 9.6 percent; people with less than a high school degree, 11.2 percent; and blue collar workers, 10.1 percent.

- Compared with 2000, a larger share of the unemployed has been jobless for more than 26 weeks, the period for which they are eligible for Unemployment Insurance benefits. In 2000, less than three-in-ten (28.0 percent) of the city's unemployed city residents had been out of work for more than 26 weeks. In 2003, that proportion climbed to four-in-ten (39.7 percent).

- Declines in jobholding since the business cycle peak of 2000 have been particularly steep for men. The employment-population ratio (the proportion of the working age population with a job) for male city residents tumbled by 5.4 percentage points compared to a 2.2 percentage point fall for women. Among New York's men the sharpest declines in employment-population ratios were for the young (a 11.6 percentage point fall), Hispanics (a drop of 7.1 percentage points) and Blacks (a 12.2 percentage point plunge). Jobholding among women has been sustained by the continued expansion of the educational and health care sectors of the city economy.

- The collapse in Black male employment in the recession was preceded by meager job growth in the prior expansion. As a result, African American men have lost ground relative to other groups in the city. In 2003 barely one-half (51.8 percent) of New York's Black men were employed. By comparison, 57.1 percent of the city's Black women and 75.7 percent of New York's White men were working in that year.

Mr. Chairman, I seek unanimous consent to have the complete study submitted to the record. Thank you Mr. Chairman

Chairman ANDREWS. Without objection. And we thank you for your comments.

Now, I think the comments are very well taken that there is a risk that genetic testing in the wrong hands could be a Trojan horse for another form of discrimination, be it based on race or ethnicity. And we don't ever want that to happen.

Mr. Hoekstra is recognized for 5 minutes.

Mr. HOEKSTRA. Thank you very much, Chairman Andrews. Good to see you, and good to be back on the committee.

For the panel, in the definition of the bill, a family member is defined to include "a dependent child of the individual, including a child who is born or to be placed for adoption with the individual."

I am a sponsor of the bill. I think that it is important that we address this issue and we address it properly. But I am wondering whether this may be an unintentional oversight, because I am very

concerned that by including the qualifiers born to or placed for adoption, this definition, does not protect an embryo, fetus or a child in the process of adoption from genetic discrimination.

For example, if prenatal screening suggests that an unborn child carries a genetic marker for an illness, that child is still potentially the victim of discrimination on the basis of his or her genetic make-up, as is the parent.

Insurance coverage or treatments could be limited based on the results of those genetic tests until the child is “born to” the parent or a pending adoption is completed.

In that light, I would like to ask, am I reading the language correctly? And if so, I would hope that there would be broad consensus by my colleagues that this is a loophole we should close if we are to give this bill serious legislative consideration.

Mrs. BIGGERT. Thank you. We looked very closely at this. And this was a definition that the Senate put in. And we had some concerns about it. But I think it is—let me just give the explanation to that.

Mr. HOEKSTRA. Yes, I mean, just because the Senate did it doesn’t—

Mrs. BIGGERT. I know. We have to be careful in the Senate—

Mr. HOEKSTRA. We have to be careful, yes.

Mrs. BIGGERT. So I think that under that definition that every child is protected. I think that is indisputable. But the term “born to” is intentionally used to provide the broadest protection in that there simply can be no argument regarding the circumstances of birth.

While one might have used the term “natural”—and I think that years ago the use of “born to” closes the door to any arguments against protection on grounds that the child was conceived by extraordinary means, such as if parents utilized fertility treatments to have a family. And that is why that was put in, to make sure that it covers all children.

Mr. HOEKSTRA. I am not sure you have answered the question. I mean, does it—

Mrs. BIGGERT. Okay.

Mr. HOEKSTRA. The couple is expecting. There is prenatal testing done that said that this child maybe, you know, has a genetic marker indicating that there is going to be an issue or a high probability of an issue, a health issue that an insurance company is concerned about. And insurance companies are in the—you know, to kind of cut down costs.

And so, could they at that point in time provide the company or the parents with the information saying, you know, we have done this testing, we have determined that this condition exists, and therefore, we are telling you today that we will not cover the health-associated costs if this child is born to?

Mrs. BIGGERT. Okay. Well, first we have to keep in mind that the genetic information would be used to prospectively discriminate to attempt to project future risks. And since the employment is not an issue and health coverage is already assured, a fetus is essentially shielded under its mother’s current insurance law.

And in practice no provider of health-care coverage would improperly act against the unborn’s interest, both because of the

shield of the mother and the fact that after birth a child is fully protected.

Mr. HOEKSTRA. So if it is consistent with other federal rules and regulations, you would be open to having that clarified here? Because it appears that in this legislation that you may be trying to create a carve-out and saying that genetic discrimination would be allowed for these cases. Because you are clearly exempting it.

So why don't we just clarify it and say that it would also apply to unborn, the unborn?

Mrs. BIGGERT. Well, we will take a look at it. But someone's genome does not change after birth. A child's genetic information is protected, regardless of when it was obtained if it was obtained before or after.

Mr. HOEKSTRA. What I am concerned about is obtaining it before it is born and impacting potential decisions before it is born to.

Mrs. BIGGERT. Okay. We will take a look at that.

Mr. HOEKSTRA. I mean, yes, I would really like to work with you because I think the bill is very, very important. But I think that this is a loophole that needs to be closed. And I would like to work with you on preparing an amendment that we can put into the bill to cover and deal with that issue.

All right. Thank you.

Chairman ANDREWS. Yield back, Mr. Hoekstra?

Mr. Sestak is recognized for 5 minutes.

Mr. SESTAK. Thank you.

Congresswoman, I just have a short comment. First, this is important. And I would just ask to make a comment because there aren't any laws in Pennsylvania presently that prohibit this genetic discrimination in either the health insurance or employment.

But more along a personal note, I can remember about a year-and-a-half ago as I was starting my 30th or 31st year in the military when the world changed for me and my young 4-year-old daughter was diagnosed with a malignant brain tumor. And, you know, you go through the typical reactions. As a guy, did I cuddle her too hard or do something wrong?

And as you work your way through that, I can remember down at Children's Hospital someone came in one day and asked us to participate in a genetic and environmental—genetic for the family—review and test because they are trying to get to the bottom line of why these tumors happen. And only 1,500 of them happen every year, malignant brain tumors, many of them death sentences.

And I just think this bill is—not that I have much to add—goes a long way toward my daughter when she has her child is not going to be worried about a genetic testing because many are going through it today in order to ensure that, you know, without any hopefully concern under this law that I or my wife or others could be precluded from something in the future having gone under a necessary—I think necessary—review process so that her child would be able to know if there is a predilection toward it without her having to have concerns for her family or others that would be precluded from coverage or other type of discrimination in the future.

And so, not much to add, except to say thank you very much.

Ms. SLAUGHTER. I am very moved by your story. There is nothing worse than having a child who is in that kind of difficulty.

Certainly, one thing this bill will do, as you point out, when she herself goes to find a job, she will not be discriminated against because of what happened to her when she was 4 years old. And that is an important point. I think that it is one that needs to be made. Thank you very much for making it.

Mrs. BIGGERT. I think that we find that, you know, it isn't always an immediate problem, but it is what will happen to our children and grandchildren when they—if they have had a test when they are 4 years old and they go on and move to another state, whatever they are doing. It is important.

Mr. KILDEE [presiding]. Are there other members who wish to ask questions? Gentlemen?

Mr. COURTNEY. Thank you, Mr. Chairman.

And I want to thank the witnesses for their advocacy for this wonderful legislation. And, you know, coming from Connecticut, some people think we have a genetic disposition toward being obsessed with insurance. [Laughter.]

So I actually just had a question I wanted to ask you about. It is pretty clear that life insurance is exempted from the reach of this bill, and appropriately so. I mean, I think that the type of insurance where choosing risk or even avoiding risk makes sense because it is not an important issue like health insurance.

But there are a lot of employers who are involved with their workers at the time of purchasing life insurance, either through a benefit structure that they have or offer to their employees.

And looking at the employment provisions and the limitation on acquisition, I mean, I am just trying to visualize that there certainly could be instances where workers are in the process of trying to sign up for life insurance through work will be asked to take genetic tests and that information will be sort of available to employers and to insurers.

And I guess I wanted to ask Ms. Biggert because it sounds like she was working with the business community, you know, whether or not that sort of scenario was contemplated in terms of the inadvertency exemption or—because you don't want to obviously discourage people from signing up for life insurance, either.

Mrs. BIGGERT. I think that is why that was carved out, the water-cooler exemption where an employer inadvertently learns about that. And that would be a case if they learned that through the life insurance, that they could not use it. But they would not be, you know, discriminating if they just found out about it inadvertently.

But it is very important for life insurance. I mean, that is how they determine what life insurance they can give to people. So it is something that has no application here.

Mr. COURTNEY. Because, you know, if you are offering that as a benefit and people are doing it as part of a program at work, I mean, that is sort of not so inadvertent. I mean, it is more of a—

Mrs. BIGGERT. Right. Well, it is just like the wellness program that a lot of companies—and I think you will hear testimony about that later today and how they want, you know, people to get tested so that they will participate in their wellness programs and then

that will reduce the costs of health care to the employer, too, and to the insurer because if the people stay healthy it is not going to cost so much. Same thing with being able to have the life insurance.

And I would say that usually life insurance within a company is term insurance so that they are not really getting involved in asking those questions as much as if you go for outside, you know, to get life insurance as an individual.

Mr. COURTNEY. Thank you, Mr. Andrews.

Chairman ANDREWS [presiding]. Thank you, Mr. Courtney.

Thank you, Mr. Kildee, for sitting here just for a while. I don't want to give this up for too long.

Ms. SLAUGHTER. Mr. Chairman?

Chairman ANDREWS. Yes.

Ms. SLAUGHTER. May I ask unanimous consent to put these into the record?

Chairman ANDREWS. Without objection.

Ms. SLAUGHTER. And I also want to correct something I said to Mr. Kline. Like all federal insurance preemptions, any state that has stronger law, that will be the one that is in effect. Two of the 30 states already have stronger laws than this one. This would not supercede their law.

Chairman ANDREWS. Mr. Kline, since this is directed to you—

Mr. KLINE. Yes, I appreciate the chairwoman clarifying that because I think that is an issue that we are going to have to discuss. Our 50 states have different laws here, some stronger and some not. And so, I can see some potential mischief. So thank you for clarifying.

Chairman ANDREWS. I want to thank both of our colleagues for the generous amount of time they have contributed to this hearing this morning.

Mr. Kline made reference to regular order during his remarks. I support his remarks and embrace them. I think the benefits of regular order are considerable.

And this is one of the better examples of how to do regular order. Our two colleagues have spent an enormous amount of time on this issue. They have met with all different groups that have a stake and interest in the issue. I think they have produced a thoughtful, well-balanced legislative product. And they have ably answered all of our questions here this morning.

So we thank you.

And at this point, we will go to the second panel.

Ms. Biggert, you are welcome to join us on the committee.

And, Ms. Slaughter, we will see you in Rules.

Okay, I would ask the second panel to please join us at this time.

All right, ladies and gentlemen, we are going to proceed to the second panel. I would, first of all, thank our four witnesses for spending time with us today.

I know that each of the four of you are busy and have much to do with your work and your family. And we are glad that you took time with us.

You will notice in front of you there is a panel of lights. We ask the witnesses to limit their statements to 5 minutes or less. Your written statements will, without objection, be entered into the for-

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.

I was also selected as the McCook Division Employee of the Year in 1994. I had always had a great working relationship with all my coworkers as well as with the upper management team.

Prior to my departure from the company, I began experiencing numbness, pain and tingling sensations in my right hand. When the numbness began to move through my hand and up my arm into my upper bicep, I went to see a doctor who referred me to a specialist. It was determined that I had developed work-related carpal tunnel syndrome, for which surgery was necessary.

After meeting with the operating surgeon, I received a letter from corporate headquarters stating that they were not satisfied with the initial test results and that they required further testing. In a subsequent visit to a neurologist, I once again had my hands X-rayed and another nerve conductor study performed. The results again confirmed that I had carpal tunnel syndrome, that surgery was required and that the condition was work-related.

Within 3 weeks of the surgery, I received a certified letter from the management in Fort Worth, Texas, demanding that I undergo more extensive testing, and that an appointment was already set for me.

Included in this letter was the requirement of safety rule S-26.3, which gives the medical department the authority to require an employee to meet all requirements set forth by the medical department, and that everyone must comply with these instructions or face the consequences of disciplinary action for being an insubordinate employee.

After receiving the letter, I immediately contacted the company medical case manager, with whom I had been dealing, and I reminded her that I had already seen four medical professionals, undergone two nerve conductor studies, had received six separate X-rays of each hand, and now the company was demanding that I see yet a fifth doctor and undergo yet another nerve conductor study with more X-rays. When I pressed for an explanation, I was told that, as far as she understood, more information concerning my medical condition was needed.

I went to the appointment as I had been ordered. During the procedure, seven vials of my blood were extracted, and the doctor once again confirmed that I did suffer the effects of carpal tunnel syndrome, and that the condition is work-related.

In a matter of a few days, I would learn from a co-worker who had refused to submit to that same order, and who also had been diagnosed with carpal tunnel syndrome, that I had been subjected to a genetics test through the blood which was taken from me. This was done without my knowledge and without my consent.

I found myself in a state of disbelief and humiliation. I could not believe or accept what had just occurred. I experienced stages of denial, disbelief, and depression. I felt totally violated and devalued as a person. I had just been used as a laboratory rat in a carefully devised scheme where my employer would benefit greatly by trying to prove that carpal tunnel syndrome was a genetic disorder rather than a work environment-related condition.

They could relieve themselves of any financial obligations to their employees who suffer work-related injuries within the workplace.

This was a very difficult concept for me to accept. My attitude toward the company became very negative.

My moods of anger and depression resulting from the constant stress and uncertainty of my job situation affected my family as well. I became very despondent to the needs and the concerns of my wife and daughters as I tried to work through this seemingly endless situation.

I was also fearful of the fact that no one could tell me where all the vials of my blood had been dispersed, what information was being learned about me, who was going to receive this information, and how it could be used to discriminate against not only myself but my family, when they go out into the workplace.

The constant worries where would I go to find another job at this point in my life and to be able to obtain insurance for my family seemed to me an insurmountable quest. This was a very trying time in my life.

One of the most heart-wrenching moments occurred when my little 7-year-old daughter, Kristen, began crying one night because she was scared Daddy was going to lose his job and her little world would be turned upside down. How do you explain to a young child that you could lose your job not because of what you have done to your employer, but because of what your employer has done to you?

I feel that this new science of genetic information is a great asset when left in responsible hands. But it can also be very devastating when put into the hands of the wrong people. I am fearful of the power that corporations, including insurance companies, would have if they were allowed to subject their employees and policyholders to genetic testing and then make decisions based on what is learned in those tests.

We have laws to protect us from people wiretapping our phone, stealing our mail and defrauding our bank account. How can we allow employers to steal the blood of their employees and use it to discriminate through the predispositions discovered through the information learned from that genetics test?

It is my personal belief that individuals are hired on the basis of their abilities and their capabilities to do the job, not on the basis of their genetic makeup or history.

It has now been over 5 years since I had the opportunity to testify before the Health, Education, Labor and Pensions Committee in regards to genetic discrimination. To this day, I have never received confirmation of what happened to the five vials of blood taken from me. I have been denied health insurance since I am on a railroad occupational disability. And there are still no laws protecting individuals from an employer demanding an employee to be genetically tested.

There have been many important events that have occurred in this 5-year time period, most notably 9/11 and the aftermath which followed. As important of an event that this has been in our nation's history, I still strongly believe that the need for the passage of legislation that protects all Americans from genetic discrimination is as important today as it was 5 years ago.

Mr. Chairman, through the tactics of deception, intimidation, lying and stealing, the company to which I had given 26 years of

my life took from me something they can never give back. And that is the very essence of my being, my genetic makeup.

In conclusion, if employers, insurance companies and the like are able to have this type of power and control over their employees and clients, then who will be able to have a job or affordable insurance, if any insurance at all?

I want to thank the committee for the opportunity to testify. And I urge enactment on legislation to protect American citizens from the genetic discrimination. Thank you.

[The statement of Mr. Escher follows:]

Prepared Statement of David Escher, Former Employee, Burlington Northern Santa Fe Railroad

Thank you, Mr. Chairman and members of the committee. My name is Dave Escher. I am 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 with a population of 200 people. I graduated from high school there in 1972, and I began my career with Burlington Northern in 1976 and ended that career in 2002. I married my wife, Deb, in 1986, have three daughters, Kelsey, Karen, Kristen. We now live in Reno, Nevada after relocating three and a half years ago from McCook, Nebraska.

My jobs within the company have included such positions as a laborer, truck driver, assistant foreman, machine operator and foreman. I was appointed to the Division Safety Committee by the Division Roadmaster and continued for over 12 years where I held such positions as maintenance of way representative, vice chairman, and safety and health facilitator up to the time of my departure from the company. I was also selected as the McCook Division Safety Employee of the Year in 1994. I had always had a great working relationship with all my coworkers as well as those in upper management levels. A couple of years ago, I began experience numbness, pain and tingling sensations in my right hand. When the numbness began to move through my hand and up my arm into my upper bicep, I went to see a doctor who referred me to a specialist. It was determined that I had developed work-related carpal tunnel syndrome, for which surgery was necessary.

After meeting with the operating surgeon, I received a letter from corporate headquarters stating that they were not satisfied with the initial test results and that they required further testing. In a subsequent visit to a neurologist, I once again had my hands x-rayed and another nerve conduction study performed. The results again confirmed that I had carpal tunnel syndrome, that surgery was required and that the condition was work-related.

Within three weeks of the surgery, I received another letter from management demanding that I undergo more extensive testing, and that an appointment was already set for me. Included in this letter was the requirement of safety rule S-26.3, which gives the medical department the authority to require an employee to meet all requirements set forth by the medical department, and that everyone must comply with these instructions or face the consequences of disciplinary action for being an insubordinate employee.

After receiving this letter, I immediately contacted the company medical case manager, with whom I had been dealing, and I reminded her that I had already seen four medical professionals, undergone two nerve conduction studies, had received six separate x-rays of each hand, and now the company was demanding that I see yet a fifth doctor and undergo yet another nerve conduction study with more x-rays. When I pressed for an explanation, I was told that as far as she understood, more information concerning my medical condition was needed. I went to the appointment as I had been ordered. During the procedure, seven vials of my blood were extracted, and the doctor once again confirmed that I did suffer the effects of carpal tunnel syndrome, and that the condition is work-related. In a matter of a few days, I would learn from a co-worker who had refused to submit to the same order, and who also had been diagnosed with carpal tunnel syndrome, that I had been subjected to a genetics test through the blood which was taken from me. This was done without my knowledge or my consent. I found myself in a state of disbelief and humiliation. I could not believe or accept what had just occurred. I experienced stages of denial, disbelief and depression. I felt totally violated and devalued as a person. I had just been used as a laboratory rat in a carefully devised scheme where my employer would benefit greatly by trying to prove that carpal tunnel syndrome was

a genetic disorder rather than a work environment related condition. They could relieve themselves of the financial obligations to their employees who suffer work-related injuries within the workplace. This was a very difficult concept for me to accept. My attitude toward the company became very negative. My moods of anger and depression resulting from the constant stress and uncertainty of my job situation affected my family as well. I became despondent to the needs and the concerns of my wife and daughters as I tried to work through this seemingly uncomfortable and endless situation. I was also fearful of the fact that no one could tell me where all the vials of my blood had been dispersed. What information was being learned about me, who was going to receive this information, and how it could be used to discriminate against not only myself but my family, when they go out into the work place? The constant worries, "where would I go to find another job at this point in my life," and to be able to obtain insurance for my family, seemed to me insurmountable. This was a very trying time in my life. One of the most heart-wrenching moments occurred when my little seven-year old daughter, Kristen, began crying one night because she was scared daddy was going to lose his job, and her little world would be turned upside down. How do you explain to a young child that you could lose your job not because of what you have done to your employer, but because of what your employer has done to you? I feel that this new science of genetic information is a great asset when left in responsible hands. But it can also be very devastating when put into the hands of the wrong people. I am fearful of the power that corporations, including insurance companies, would have if they were allowed to subject their employees and policyholders to genetic testing, and then make decisions based on what is learned in those tests.

We have laws to protect us from people wiretapping our phone, stealing our mail and defrauding our bank account. How can we allow employers to steal the blood of their employees and use it to discriminate through the predispositions discovered through the information learned from the genetic studies?

It has now been over 5 years since I had the opportunity to testify before the Health, Education, Labor and Pensions Committee in regards to genetic discrimination. There have been many important events that have occurred in this time period, most notably 9/11 and the aftermath which followed. As important of an event that this has been in our Nation's history, I still strongly believe that the need for the passage of legislation that protects American citizens from genetic discrimination is as important today as it was 5 years ago.

In conclusion, if employers, insurance companies and the like are able to have this type of power and control over its employees and clients, then who will be able to have a job or affordable insurance, if any insurance at all?

Chairman ANDREWS. Mr. Escher, thank you. And let me say how proud I am sure your family is of you, that you have shown the integrity and strength to come tell your story in a way that will hopefully help others avoid the difficulties that you faced. I am sure your family is very proud of you. You did a very fine job.

Mr. ESCHER. Thank you.

Chairman ANDREWS. Ms. Pearson, welcome.

STATEMENT OF HARRIET PEARSON, VICE PRESIDENT OF CORPORATE AFFAIRS AND CHIEF PRIVACY OFFICER, IBM CORP.

Ms. PEARSON. Thank you. And good morning, Mr. Chairman and members of the committee. My name is Harriet Pearson. I am the chief privacy officer and vice president of corporate affairs at IBM. And we are honored to have been asked to come and share our experience with our own policies and offer our views on H.R. 493, the Genetic Information Nondiscrimination Act. We appear here in support of the need for the legislation.

IBM is a globally integrated enterprise with 340,000 employees around the world. We provide access to health-care coverage for more than 500,000 employees, IBMers, family members and dependents. We follow rigorous health privacy policies and practices.

And we do not—let me clarify—we do not seek to collect genetic information. On October 2005, IBM became the first major corporation, to my knowledge, to make genetic nondiscrimination part of our official employment policy.

As our chairman and CEO, Sam Palmisano, said in his letter to employees, “It has been IBM’s long-standing policy not to discriminate against people because of their heritage or who they are. A person’s genetic makeup may be the most fundamental expression of both. So we are taking this step because it is the right thing to do for the sake of the innovation that lies just over the horizon, and because it is entirely consistent with our values and with who we are as a company.”

The entire note that Mr. Palmisano wrote to our employees is attached as an appendix to my written statement, which I have submitted for the record.

In our policy, IBM has taken the position that genetic information will not be used in hiring, in determining employees’ eligibility for health-care coverage or in making other employment decisions.

The reaction among our employees, among health and privacy experts and others to our position has been positive. I personally reviewed about 100 letters from different employees to our chairman appreciating the move that we made.

And one in particular, for example, was an employee who has Huntington’s in his family, who thanked the company, thanked IBM for making the certainty that he could work in a company and not have to face the risk or the uncertainty of any consequences.

But he asked the question, which made us think, you know, what about his child, what about his children? And that really rose, you know, to my attention as really the example of why we potentially would need more policy in the United States.

So far, I have to say, in terms of costs to us as an employer, we have not experienced, as I said, any negative reactions or any costs that I can point to related to our position on this issue. The reasons for making genetic privacy part of our broader discrimination protections were clear to us.

First, we believe that a person’s genetic profile should be treated the same as other innate human characteristics such as one’s race, gender, national origin, sexual orientation, age or physical abilities. Simply stated, a person’s genetic profile is as natural and as inseparable from who they are as any other physical trait or attribute.

Second, it is even more important to protect people’s genetic privacy as medicine and science further reveal the relationship between specific diseases and an individual’s unique genetic fingerprint. We at IBM know this because our own experts and technologies are involved in a range of efforts from gene sequencing to personalized medicine. We even have a computer named Blue Gene.

For example, our experts in health care and life sciences are collaborating with researchers at centers around the world, such as the Mayo Clinic and the Karolinska Institute in Sweden, to unlock the molecular roots of disease with the help of genetic data.

There is little disagreement, we believe, in Congress or across the country, that each of us should be protected from discrimina-

tion based on our genetic makeup. As we discovered in setting our own policy at IBM, there is value and security in clarifying that such discrimination will not be practiced or tolerated.

A powerful reason for Congress to act on genetic nondiscrimination now is that this issue is bound to become a bigger challenge as we move into the future of information-based medicine. In this new age, genetic screening will be used more routinely in the diagnosis and treatment of disease, and test results will increasingly exist in electronic or digital format.

By setting a national policy we may even improve patient care. People with genetic predispositions toward diseases such as diabetes or heart disease could seek preventative treatment without fear of the consequences to their employment or access to health insurance.

By establishing that none of us can be discriminated against on the basis of the genes we are born with, we also will create the safe foundation for future therapies that could repair or address the genetic defects that might make us prone to particular diseases. The era of genetic medicine is probably closer than we think. We need to create the social and legal environments that will be conducive to it.

When we instituted our policy in 2005, many people asked, why do we need such protections now before genetic discrimination is a wide concern? I will echo some of the comments you have heard before by saying that, you know, for us, the answer was that we had a sense of what is going on in the environment out there. And, for us, the answer was also that matters of policy are not about reacting to external pressures, but following the logic of our company's inherent values.

In IBM's early days we instituted equal opportunity policies that prohibit discrimination on the basis of race or gender. That was decades before such policies were mandated by law. And we did it because it was the right thing to do. Because they are implicit in our company's core values. And we have stood by them for decades now. And we have a great record in that space.

Chairman ANDREWS. Ms. Pearson?

Ms. PEARSON. In our view—

Chairman ANDREWS. I am sorry. If you could wrap up. Thank you.

Ms. PEARSON. Yes. Not protecting anybody's genetic privacy and IBMers' genetic privacy would have been inconsistent with our own DNA as an organization. In that light, it is the right time for Congress to address this issue. And we support H.R. 493 and would offer a few observations, which are in our written statement.

And I will conclude with a practical observation, that, as we all know, any legislation that expands requirements or liability can have unintended consequences. And Congress should closely monitor implementation of the law by the responsible agencies. And there should be a watchful eye against unnecessarily expansive interpretation and the resulting burdens that might be imposed.

We believe that protecting genetic privacy and protecting against nondiscrimination is a compelling issue though at the moment. And therefore, we appear in support of H.R. 493.

Thank you for the opportunity to testify this morning.

[The statement of Ms. Pearson follows:]

Prepared Statement of Harriet Pearson, Vice President of Corporate Affairs and Chief Privacy Officer, IBM Corp.

Chairman Andrews and members of the Subcommittee on Health, Employment, Labor and Pensions. My name is Harriet Pearson, and I serve as IBM's Chief Privacy Officer, and as Vice President of Corporate Affairs.

IBM appreciates the opportunity to testify in this hearing on H.R. 493, the Genetic Information Nondiscrimination Act of 2007. IBM supports the legislation.

IBM is a globally-integrated enterprise engaged in business and technology innovation with more than 340,000 employees. We provide access to healthcare coverage to more than 500,000 IBMers, their families and dependents.

On October 9, 2005, IBM became the first major corporation to make genetic non-discrimination part of our official employment policy. As our chairman, Sam Palmisano, said in his letter to employees:

"It has been IBM's long-standing policy not to discriminate against people because of their heritage or who they are. A person's genetic makeup may be the most fundamental expression of both. So we are taking this step today because it is the right thing to do—for the sake of the innovation that lies just over the horizon, and because it is entirely consistent with our values and with who we are as a company."

(The entire note is attached as an appendix to this document.)

Reaction among IBM employees, health and privacy experts and others to our leadership on this issue has been uniformly positive. Let me cite two examples:

- An IBM software employee wrote: "you make me proud to be an IBM employee. I will be sharing this with my friends outside of IBM as an example of how my company can choose to put its people first and do the right thing."
- One IBMer wrote to Sam Palmisano: "as a deaf employee, I would like to extend a deep and sincere thank you for ensuring that my rights are protected, even indirectly, through this policy."

In our policy, IBM has taken the position that genetic information will not be used in hiring, in determining employees' eligibility for health care coverage or other employment benefits, or in other employment decisions to which such information is not relevant.

The reasons for making genetic privacy part of our broader discrimination protections were clear to us: first, we believe that a person's genetic profile or makeup should be treated the same as other innate human characteristics, such as one's race, gender, sexual orientation, age or physical abilities.

Simply stated, a person's genetic profile is as natural and as inseparable from whom they are as any other physical trait or attribute.

Second, it is even more important to protect people's genetic privacy as medicine and science further discover the relationship between specific diseases and an individual's unique genetic fingerprint.

We know this because IBM technology underlies many genetic breakthroughs from gene sequencing to personalized medicine.

For example, our experts in healthcare and life sciences are working with medical researchers at centers around the world, such as the Mayo Clinic and the Karolinska Institute in Sweden to harness genetic insights to unlock the molecular roots of disease.

Common Genetic Tests Today	Emerging Tests and Genetic Screening
Huntington's Disease	Bowel Cancer (University of Edinburgh)
Cystic Fibrosis	Ocular Melanoma (UCLA's Jules Stein Eye Institute)
Breast Cancer, presymptomatic testing	Human Papillomavirus (Roche)
Prenatal Genetic Screen	Fragile X Syndrome (U.S. Genomics & Quest Diagnostics)
Pre-Implantation Testing of Embryos	Early Stage Lung Cancer (University of Maryland School of Medicine)

One innovation front we are leading is to enable genetic data to be securely and anonymously integrated with other types of healthcare data such as electronic medical records. This approach holds considerable promise both for saving individual lives and for speeding medical breakthroughs.

Today, there are genetic tests for almost 1000 diseases,¹ and several hundred more are under development. The results can help confirm conditions and inform treatment decisions. In other instances they can quantify the risk of future disease.

¹The Genetics & Public Policy Center.

Some genetic tests under development aim to predict the responsiveness of drugs for heart disease, cancer, asthma and other conditions.

The danger of not safeguarding genetic information is the potential that a person with a genetic predisposition toward one or more diseases might be denied healthcare insurance, lose their job or be turned down for one.

Genetic data or tests results should also be shielded because in many instances they only suggest a risk of developing a disease. It is our view that no one should lose their health insurance or their livelihood because they have a statistical chance of becoming diabetic, arthritic or asthmatic. Instead, such information can be—and should be—used to the positive ends of enabling preventive lifestyle changes or potentially tailoring medical or pharmaceutical regimens that reduce the risk of the condition at issue developing.

As Francis Collins, Director of the National Human Genome Research Institute noted in 2003, in “A Brief Primer on Genetic Testing”:

Applied properly, [genetic testing] could usher in a new era of individualized preventive medicine that could have considerable health benefits. It will be important to remember, however, that most of these tests will not be “yes or no” but rather will predict relative risk. For this paradigm to succeed, it will also be essential that predictive genetic information is used to benefit individuals, rather than to injure them by discriminatory misuse.

There is little disagreement, we believe, in Congress or across the country, that each of us should be protected from discrimination based on genetic makeup. As we discovered in setting our own company-wide policy, there is value and security in clarifying that such discrimination will not be practiced or tolerated.

A powerful reason for Congress to act on genetic nondiscrimination now is that this issue is undoubtedly bound to become a bigger challenge as we move into the future of information-based medicine, where genetic screening or tests will be used even more routinely in the diagnosis and treatment of disease.

In fact, by setting a national policy that one’s genetic data should not lead to discrimination in the workplace and health insurance market, we may improve patient care: people with genetic predispositions toward chronic diseases such as diabetes or heart disease could seek preventative treatment without fear of the consequences to their employment or access to health insurance.

What I.B.M. is doing is significant because you have a big, leadership company that is saying to its workers, ‘We aren’t going to use genetic testing against you,’ said Arthur L. Caplan, director of the Center for Bioethics at the University of Pennsylvania medical school. ‘If you want a genomic revolution,’ Mr. Caplan added, ‘then you better have policies, practices and safeguards that give people comfort and trust.’—The New York Times, October 10, 2005.

By firmly establishing that none of us can be discriminated against on the basis of the genes we are born with and have no real control over, we also will create the safe foundation for future therapies that could repair or address the genetic defect that might make us prone to particular diseases or ailments.

The era of genetic medicine is probably closer than we think. In order for society to benefit from, and be prepared for, such profound innovations in healthcare, we need to create the social and legal environment that will be conducive to it.

When we instituted our policy in 2005, one of the biggest questions it raised was “why do we need such protections now, in advance of genetic discrimination being commonplace?”

For IBM, the answer was that matters of policy are not about reacting to external pressure, but following the logic of the company’s inherent values. From IBM’s early days, we instituted equal opportunity policies, policies that prohibit discrimination on the basis of race or gender for example, decades before they were mandated by law, because they were the right thing to do, because they were implicit in the company’s core values.

Today, two of IBM’s core values—values that were shaped by the entire IBM population via online collaborations called “jams”—provide clear direction for our path as an organization. Those values are ‘innovation that matters—for our company and for the world’ and ‘trust and personal responsibility in all relationships.’ In our view, not protecting IBMers’ genetic privacy or not including genetics in our equal-opportunity policy would have been inconsistent with our own DNA as an organization.

IBM Employment Policy Milestones

1914—IBM hires its first employee with a disability

1953—IBM establishes a formal equal opportunity policy

1984—IBM adds sexual orientation to company policies regarding non-discrimination policy

2005—IBM adds genetic privacy to company policies regarding non-discrimination policy

In addition, in the little more than a year since our announcement, new genetic markers for diseases such as diabetes, Alzheimer's and others have demonstrated that we certainly weren't too early.

In that light, it is the right time for Congress to address this issue head on, and make genetic discrimination part of the protections we as Americans have against biases that run counter to Americans' shared values of fairness and merit-based decisionmaking.

IBM supports H.R. 493, The Genetic Nondiscrimination Act of 2007, and has the following practical observations to share:

- There is the potential for confusion or overlap because individuals could seek remedies for claims of genetic discrimination through the provisions in the legislation, as well as through existing legislation such as the Americans with Disabilities Act.

- Genetic information is defined broadly as the occurrence of a "disease or disorder in family members of an individual." That description may not reflect the increasingly unique, individual nature of genetic data and personalized medicine.

- Congress should also closely monitor implementation of the legislation by the responsible federal administrative agencies to ensure there are no expansive interpretations which could create unanticipated burdens on the employer community. Any legislation that includes new expansions in liability can create costs that are burdensome.

Protecting genetic privacy is an opportunity for our nation to lead on a front that is almost certain to become a global challenge, and for us to chart a course that expands the range of individual liberties that are at the heart of the American ideal.

There have been relatively few times in our history when the significance of a major technological breakthrough could be understood from the get-go. The times have been even fewer when societal and political conditions at that same moment were ripe for enlightened planning. We usually legislate by hindsight. Because we usually acquire the wisdom to shape and protect a scientific breakthrough only decades after it has broken through. Today, with this technology, with this issue, and with this legislation—properly improved—Congress has the chance to do so.

Thank you. And now I'm happy to answer any questions.

APPENDIX

To: IBMer US 0051; IBMer US 0052; IBMer US 0053; IBMer US 0054; IBMer US 0055.

Subject: Protecting Genetic Privacy

DEAR IBMER: During our lifetimes, the practice of medicine and society's approach to healthcare have changed in fundamental ways. But what lies ahead—perhaps in the next decade alone—seems likely to eclipse that progress dramatically.

Along with any change in an important area of science or society, new and often difficult policy questions inevitably arise. And that's uniquely so for healthcare. Business, government and the research community have a responsibility to address these issues. I am writing today to tell you about an important step that IBM is taking to do so.

Of all the work now taking place across the life sciences, none perhaps has the transforming potential of the pioneering efforts to unlock the secrets of the human genome. IBM is already engaged in many of the technology innovations springing from the revolution in genetics and IT—from "information-based medicine" (which seeks to transform care by marrying genomics with clinical treatment); to our Geographic Project, where we're helping National Geographic to map the scientific history of our genes' migration; to the innovation flowing from our Blue Gene super-computer.

This work is enormously promising—but it also raises very significant issues, especially in the areas of privacy and security. The opportunity the world has to improve life in the century ahead through genomics-driven, personalized medicine and preventive care will only be realized fully if it also takes into account the protection of genetic privacy. We must make this a priority now.

For that reason, I have signed a revision of IBM's equal opportunity policy, first published by Thomas J. Watson, Jr., in 1953. IBM is formally committing that it will not use genetic information in its employment decisions, a policy we believe is the first of its kind for a major corporation. You should know that IBM does not actively seek to collect genetic information—but at times, and increasingly in the future, employees or their family members may choose to share it, for example, in

order to facilitate participation in information-based wellness programs. In anticipation of such circumstances and other situations that we cannot fully anticipate, we are today establishing that business activities such as hiring, promotion and compensation of employees will be conducted without regard to a person's genetics.

It has been IBM's long-standing policy not to discriminate against people because of their heritage or who they are. A person's genetic makeup may be the most fundamental expression of both. So, we are taking this step today because it is the right thing to do—for the sake of the innovation that lies just over the horizon, and because it is entirely consistent with our values and with who we are as a company.

SAMUEL J. PALMISANO,

Chairman and Chief Executive Officer, the Genetics & Public Policy Center.

Chairman ANDREWS. Ms. Pearson, thank you very much. And your full statement has been entered into the record.

Ms. PEARSON. Thank you.

Chairman ANDREWS. Mr. Fishman, your full statement has been entered into the record, and we welcome you to the committee.

STATEMENT OF BURTON J. FISHMAN, PARTNER, FORTNEY SCOTT LLP, GENETIC INFORMATION NONDISCRIMINATION IN EMPLOYMENT (GINE) COALITION

Mr. FISHMAN. Well, thank you, Chairman Andrews, Ranking Member Kline, distinguished members of the subcommittee. Thank you for this opportunity to testify this morning on behalf of the Genetic Information Nondiscrimination in Employment Coalition, the GINE Coalition.

Let me state at the outset, and let me be clear, the GINE Coalition strongly supports genetic nondiscrimination and confidentiality and believes that employment decisions should be based on an individual's qualifications and ability to perform a job, not on characteristics that have no bearing on job performance, period.

Although this is not a legislative hearing, we are aware that Representative Biggert and Representative Slaughter have introduced H.R. 493. The coalition commends the goals of that bill. And we hope to continue working with the sponsors, the members of this committee, all of Congress in making genetic discrimination legislation more effective, administratively efficient and practical.

Thank you for accepting my statement. I do not intend to repeat it, but I do want to address a few of my comments to issues that the coalition regards as significant, which are also part of the proposed bill.

When testimony was given about a prior version of this bill in 2004, it was noted that over 30 states had passed genetic discrimination laws covering scores of millions of people. At that time, not a single case had been brought under any of those laws, let alone a violation being found.

That remains true today. Indeed, the fact that we have heard again this morning about conduct at Burlington Northern in 2000 and 2001 serves for me to underscore the rare and unrepeatable nature of that event.

We believed then and now that the bill is a remedy in search of a problem. Nevertheless, it appears that you have decided that federal legislation is necessary. And as a coalition that opposes employment discrimination, we do not oppose the bill.

However, we do believe the proposed bill can be strengthened. And we wish to work with you to craft a more effective and more meaningful bill.

For example, we share the concerns of some of the prior witnesses. We hope Representative Biggert makes very clear in future drafts of the bill that this law is directed solely against intentional and deliberate discrimination. We believe that it should.

We hope Representative Slaughter clarifies her position so that the bill has nationally preempted effect. There should be one standard, and it should be your standard.

We agree with Representative Price that one of the unforeseen consequences is that beneficial medical outcomes may be in peril.

We concur with the written statements of Professor Rothenberg which state that employers should be able to collect genetic information if they can show that such information is relevant to the job, worker safety requires it.

And we agree with Ms. Pearson, again, in her written testimony that this bill creates confusion and overlaps, that the definitions are too broad and that these vagaries will lead to needless burdens and costs to employers.

Like them, we do not want the law that imposes real burdens and actual costs based on distant, contingent eventualities or the inadvertent conduct of any employer without your due deliberation. We do not want a law that makes knowledge illicit rather than one focused on illicit conduct. And since there has never been an opportunity for lawsuits without there being lawsuits, we do not want new causes of action, particularly for technical violations without your due deliberation.

And I raise these points because the proposed bill could be improved, we think, by greater attention to the implications of some of the propositions.

For a few more examples, the definition of family member is virtually limitless, including fourth cousins thrice removed. We do not think that is what you intended. But that is what is there.

There is the new requirement for confidential segregated record keeping of genetic information as distinguished from health information. Even if laymen could make that distinction, we hope that these rare documents can be included with other confidential health records in already confidential files.

And we more sincerely hope that you do not permit compensatory and punitive damages for technical violations. Punish discrimination; do not punish bad filing.

Genetic information acquired pursuant to some laws from some sources such as FMLA certification is permitted. But the same information from more likely sources—ADA accommodations discussions, discussions about health insurance under HIPPA and COBRA—are not permitted. There should be an exception permitting the acquisition of all such information if relevant to the job, if collected pursuant to law and retained in confidential files.

The information should not be the issue. The misuse of the information should be the issue.

I mentioned the soaring number of state laws. This subcommittee knows the virtue and the importance of preemptive fed-

eral standards. If new burdens are put on employers, at least let them have a single standard.

And finally, please remember there will be a time not too far off, I hope, when the rapid, untrammled dissemination of genetic information will save lives. Do nothing here that even threatens to delay that hour. The product of genetic research is not discrimination. It is saving lives. Do nothing that curtails that research or limits the free flow of life-giving information. Make discrimination illegal, not knowledge.

Thank you for this opportunity, Mr. Chairman. And I will be happy to answer any questions you may have.

[The statement of Mr. Fishman follows:]

**Prepared Statement of Burton J. Fishman, Partner, Fortney Scott LLP,
Genetic Information Nondiscrimination in Employment (GINE) Coalition**

Chairman Andrews, Ranking Member Kline, and distinguished members of the subcommittee. Thank you for this opportunity to testify on the issue of genetic discrimination in the workplace. I commend the subcommittee for holding its first hearing of the 110th Congress on this important topic. My statement will focus on the potential impact genetic nondiscrimination legislation will have on employers, employees, and their organizations.

My name is Burton Fishman. I am Of Counsel to the Washington, D.C. law firm of Fortney & Scott. By way of introduction, I served as Deputy Solicitor for National Operations at the U.S. Department of Labor under Secretary Lynn Martin, during the term of President George. H. W. Bush. I was "present at the creation" of the Americans with Disabilities Act (ADA) and have remained involved in the administration and application of that law. I have written numerous books and articles on the subject and have been involved in a number of matters with respect to the statute. That background served as a natural preface to my concerns with the issue and the bill before you today.

I appear before you this morning as Counsel to the Genetic Information Nondiscrimination in Employment Coalition, the GINE Coalition, which is a business coalition of trade associations, professional organizations, individual companies and their representatives, including the Society for Human Resource Management (SHRM), the U.S. Chamber of Commerce, The National Association of Manufacturers (NAM), and the College & University Professional Association for Human Resources (CUPA-HR), to name a few. In addition to the hundreds of thousands of members of those associations and the millions of employees they employ, representatives from biotechnology, pharmaceutical research, health care, information technology, and other industries have joined in the Coalition's deliberations. The exclusive focus of the GINE Coalition is the issue of genetic non-discrimination in employment. The Coalition has worked diligently and faithfully with all participants in the debate on the substance of federal legislation on the subject of genetic nondiscrimination. Today's testimony before the Committee is limited to that issue.¹

Let me be clear from the outset: the GINE Coalition strongly supports genetic nondiscrimination and confidentiality. The Coalition believes that employment decisions should be based on an individual's qualifications and ability to perform a job, not on characteristics that have no bearing on job performance.

Background

Members of the GINE Coalition, like the rest of society, are thrilled by and enthusiastically support the scientific research and truly spectacular breakthroughs relating to the sequencing of the human genome. Scientists in academia and industry have identified genes responsible for diseases from deafness to kidney disease to cancer. Through their efforts, we are uncovering hereditary factors in heart disease, diabetes, Parkinson's disease, bipolar illness, asthma, and other common illnesses of our society. As Dr. Francis Collins predicted a few years ago:

"Quite possibly before the end of the first decade of this new millennium, each of us may be able to learn our individual susceptibilities to common disorders, in some cases allowing the design of a program of effective individualized preventive medicine focused on lifestyle changes, diet and medical surveillance to keep us healthy. This will also enable us to focus our precious health care resources on maintaining wellness, instead of relying on expensive and often imperfect treatments for advanced disease.

“These same discoveries about genetics will lead us to predict who will respond most effectively to a particular drug therapy, and who may suffer a side effect and ought to avoid that particular drug. Furthermore, these remarkable advances will lead us to the next generation of designer drugs, focused in a much more precise way on the molecular basis of common illnesses, giving us a much more powerful set of targeted interventions to treat disease. (Testimony of Dr. Francis Collins before the Senate Health, Education, Labor and Pension Committee, July 20, 2000).”

One comes away from such predictions with an exhilarating sense of hope and optimism for the future of medical science. Every human being has one or more defective genes, or genetic “markers,” indicating a predisposition to certain abnormal traits or conditions. Given the rapid pace of genetic discoveries, in the near future, we hope, the hereditary basis for many of the profound diseases which afflict us today will not only be identified, but such knowledge will also be useful for purposes of prevention and cure. At that time, such genetic information will be vital to an individual and his/her physician, and perhaps also to the individual’s employer. The information could be used for purposes of preventing exposure to conditions in the workplace that would accelerate the onset of a particular disease or, as Dr. Collins suggested, for the purpose of fashioning individualized, employer-provided wellness programs to help prevent the disease from occurring.

However, this exhilaration is compromised by a bill, such as H.R. 493, the Genetic Information Nondiscrimination Act of 2007, which characterizes certain genetic information as “forbidden” and penalizes the flow of information. Our concern is that the very progress in medical science that Dr. Collins envisions will be delayed and deterred by legislation such as has been proposed here.

We recognize that there is a fear that genetic information may be used by employers not for beneficent purposes, but as the basis for employment discrimination. In the research community, the concern is that such fears will discourage individuals from participating in genetic research and testing. Such fears are fed by anecdotal but apocryphal stories and, of course, on the rare but highly publicized case involving Burlington Northern-Santa Fe Railroad, from nearly a decade ago.² The fact that the employees in this case were able to seek and gain redress under current law indicates that no additional legislation is required. As significant, the very fact that we hear from one of the Burlington Northern employees at this hearing underscores that what occurred there was an unusual and unrepeated event, one that should not serve as the basis for sweeping legislation.

Indeed, there are surveys conducted by neutral bodies such as the American Management Association which show that few employers seek or even understand genetic information. Further, in the more than 30 states which have laws prohibiting genetic discrimination, there have been no reported cases, even though several statutes were enacted decades ago. Thus, there is no empirical evidence of genetic discrimination in employment, unlike the mountains of evidence of discriminatory conduct which preceded passage of other nondiscrimination laws, such as Title VII of the 1964 Civil Rights Act, the Age Discrimination in Employment Act, and the Americans with Disabilities Act.

Somewhere in the distracting mix of irrational fears, a rational understanding of the benefits of genetic research has been lost. Somewhere, the legitimate concern for worker safety by government and by employers has been overlooked and replaced with notions of the sanctity of the genome. But the product of genetic research is not employment discrimination. The product of genetic research will be to help people—employees and employers—make health-giving choices based on shared knowledge. But viewed through the distorting prism of H.R. 493, the response to advances in genetic research is to prohibit the spread of knowledge. H.R. 493 responds to fear and ignores hope. It limits the spread of knowledge in the name of worker fear rather than finding ways of applying that knowledge in the name of worker safety. That is not how Congress has responded in the past and should not be how Congress responds today. Fear should not be the predicate for federal legislation.

This is particularly true in the still-nascent field of genetic testing. Currently, the predictive ability of genetic tests and other forms of genetic information has little practical workplace utility since, in the current state of medical and scientific diagnostics, genetic tests reveal only the possibility that a particular trait, condition, or illness may develop in the future. There is no medical certainty that such illnesses will, in fact, ever develop; neither is there any certainty as to how far in the future they would become manifest. Thus, such information is simply too remote and too speculative on which to base current employment decisions, even if an employer were interested in doing so—a conclusion utterly unsupported by actual conduct. Furthermore, because of the awe-inspiring speed at which scientific knowledge is expanding, legislation based on today’s understanding will likely respond to a sci-

entific context that has already fallen into obsolescence. In fact, many of the states which passed legislation early on, have already had to amend laws rendered obsolete by the advance of scientific knowledge.

Yet, it is the opinion of the sponsors and supporters of pending federal genetic nondiscrimination bills that such legislation is necessary. Although we do not share that view, as a coalition that stands squarely against employment discrimination, we do not oppose the pending legislation. However, we believe the proposed bill can be improved. We hope to work with Congress to craft an effective, efficiently administered, practical law that avoids unintended consequences and baseless lawsuits, and which will not impede progress in science.

The GINE Coalition's position on genetic nondiscrimination

The GINE Coalition has developed a set of core principles by which it measures genetic nondiscrimination legislation. The Genetic Information Non-Discrimination in Employment (GINE) Coalition endorses the following legislative principles:

- The members of the coalition believe that employment decisions should be made based on an individual's qualifications and ability to perform a job, not on the basis of characteristics that have no bearing on job performance. Therefore, we strongly oppose employment discrimination on the basis of a person's genetic makeup.

- Possession of genetic information must be differentiated from the use of this information for discriminatory purposes. Any proposed statute should be directed at controlling discriminatory conduct, rather than attempting to regulate the flow of information. As we like to say, genetic discrimination is about discrimination, not genetics.

- We believe that genetic discrimination is wrong, and if a company does intentionally discriminate, remedies should be available. However, the coalition would oppose legislation that would provide unlimited punitive and compensatory damages for victims of genetic discrimination, or that would expose employers to baseless litigation. Furthermore, no employer should be at risk of liability for inadvertently receiving information that is deemed "genetic."

- Duplicative efforts to guard against genetic discrimination are costly and confusing. Any legislative proposals regarding genetic discrimination should take into account the protections already offered by the HIPAA and its regulations, the ADA, and other federal, state, and local statutes and regulations.

In sum, the GINE Coalition's Statement of Principles embraces the letter and spirit of nondiscrimination and espouses the idea that discrimination, not information, should be the target of any such legislation. These principles are explained in more detail as follows.

Let me state again, the GINE Coalition supports the policy of nondiscrimination in employment based on an individual's genetic makeup or pre-disposition to certain diseases or conditions. Employment decisions should be based on an individual's qualifications and ability to perform a job, not on the basis of other characteristics or imputed attributes that have no bearing on job performance.

Further, being mindful of the rapid developments in genetic research and Dr. Collin's predictions regarding the beneficial use of genetic information in the near future, we believe that genetic non-discrimination legislation must be carefully and narrowly drafted. Possession of genetic information must be differentiated from the use of such information for discriminatory purposes. Legislation should be directed at controlling and punishing discriminatory conduct, rather than regulating and burdening the flow of information. The law should not trigger liability based on an employer's mere receipt of genetic information, such as through conversations concerning a relative's illness or derived from such normative behavior as visiting the sick and consoling the bereaved.

Thus, our hope today is to sound a note of caution and urge this Committee to carefully consider the impact of its actions. In light of the absence of any evidence of the use of genetic information for discriminatory purposes, there is no urgent need to act speedily.

As Congress has the time to act with deliberation and care to draft a law, I urge the subcommittee to ensure that any genetic discrimination legislation excludes any unnecessary and detrimental provisions which would:

1. Expose employers to punitive damages for technical violations;
2. Mandate that employers provide health coverage of all genetic disorders;
3. Create conflict among Federal laws and between Federal and state standards;
4. Fail to provide a single Federal standard;
5. Permit receipt of genetic information under the FMLA, but not with respect to the ADA, HIPAA, and other more likely sources of such information;
6. Adopt an overly broad definition of "family member;" and

7. Require employers to process genetic information and health care information in different ways.

Punitive damages for technical violations

All parties share the goal of eliminating discrimination any in the workplace, from the hiring process to providing benefits. When a company intentionally discriminates, remedies should be available. However, the Coalition opposes legislation that that would expose employers to baseless litigation and would provide punitive and compensatory damages absent actual discrimination. The receipt of genetic information as part of an ADA accommodation dialogue should not create even the possibility of conduct violating any law. Assisting an employee receive health insurance coverage should never give rise to a cause of action. Given the availability of significant protections under other laws, administrative enforcement and equitably based remedies (including loss of wages and benefits) should be sufficient to allay fear of possible discrimination while mitigating the risk of a dramatic increase in baseless and inherently expensive litigation. Unfortunately, the House bill resorts to jury trials with punitive and compensatory damages for any violation, without distinction, which will necessarily invite additional litigation.

Mandate to cover all genetic conditions

The driving force behind the Genetic Information Nondiscrimination Act has not been a rash of genetic discrimination cases or mishandling of genetic information, but, rather, the fear of possible discrimination which may deter employees from availing themselves of genetic tests. Therefore, the Coalition strongly believes it is in all parties interest that the bill only should prohibit employers from discriminating based on genetic tests, not family history that could be—and most times is—completely unrelated to tests, usually anecdotal, and often erroneous. This limitation would greatly minimize the opportunity for unintended consequences and unnecessary litigation under the bill, while also thoroughly addressing the issue which generated the bill. It would also greatly reduce the probability that the bill will conflict or complicate compliance with other laws.

As proposed, the House bill could permit plaintiffs to sue an employer for offering health benefits that do not cover treatment for a specific genetic condition. This provision would serve as a de facto federal mandate requiring employers to offer health plans covering all treatments for all genetic related conditions. Members of the subcommittee may recall that President Clinton in Executive Order 13145, barring genetic discrimination against federal employees, specifically exempted the Federal government from being compelled to provide such coverage and from any resulting law suits.³ We urge that this bill should provide for similar protections in the private sector and to all states and political sub-divisions.

Conflict among Federal laws and between Federal and State standards

Should a new federal genetic discrimination law be enacted, the Coalition believes it is essential that it be made to precisely mirror the requirements and protections of existing employment statutes and that it not conflict with current laws or disrupt existing nondiscriminatory employment practices.

As a practical consideration, there is always concern that new employment legislation will be drafted without due consideration being given to its impact on and its interaction with existing laws. The interrelationship and interaction among the ADA, FMLA and state workers' compensation law, all of which impose different legal requirements, demonstrates this problem. Because each law was passed at a different time and has a different policy objective, an employer's efforts to comply with one law can easily cause it to be in conflict with provisions of the other laws. Employment laws are most effective when compliance with one federal or state law does not contradict other laws or does not require employers to violate one law to satisfy another.

Any genetic nondiscrimination legislation must be balanced, objective, and developed with existing law in mind. Any legislative proposals regarding genetic discrimination should take into account and be in accordance with the protections already offered by the HIPAA and its regulations, the ADA, and other federal, state, and local statutes and regulations. Duplicative efforts to guard against genetic discrimination are costly, confusing, and unnecessary.

Lack of a single Federal standard

H.R. 493 would not create a single federal standard, but unfortunately would allow a patchwork of state standards to impose inconsistent requirements. Any Federal legislation should recognize the problems faced by employers as they try to comply with the numerous genetic discrimination laws already in existence. More than 30 states have enacted laws prohibiting discrimination based on genetic infor-

mation. However, these laws vary widely. If Congress enacts legislation barring employment discrimination based on genetic information then it should include a safe harbor providing that employers in compliance with the federal standards cannot be liable under state or local laws banning such discrimination. There should be only one standard, your standard.

Permitting receipt of genetic information

Under the proposed bill, genetic information may lawfully be acquired from some sources, such as FMLA medical certifications and workers' compensation forms, whereas the same information from more likely sources, such as employer-provided sick or family leave that is not FMLA qualifying, ADA accommodations or discussions regarding health insurance coverage under HIPAA or COBRA, is not allowed.

The interplay of the proposed legislation and the ADA and HIPAA creates significant difficulties. Employer efforts to make timely and accurate determinations regarding requests for accommodations or claims brought under current law should not be inhibited or made illicit.

Finally, many employers provide leave for illnesses not covered by the FMLA, or beyond what is mandated by the FMLA for medical and family reasons or provide similar leave but fall below the 50 employee threshold under the FMLA. In order to administer these leave programs, employers routinely require employees to provide documentation of the need for leave. Exposing employers to liabilities for requiring documentation will discourage them from offering these leave benefits.

It is imperative that legislative efforts be focused on prohibiting the discriminatory use of genetic information, not on the flow of such information. There should be a broad exception permitting the acquisition of all such information, if collected pursuant to law and retained in confidential files. The information should not be the issue; the misuse of the information should.

Expansive definition of family member

If there must be a cause of action based on family history, then it should be of reasonable scope. The Coalition believes that any legislation should only cover instances in which information is scientifically proven to reveal patterns of inheritance of genetic conditions and is useful for medical diagnosis of the employee and his or her immediate family. Unfortunately, the House bill defines "family member" as all "individuals related by blood to the individual or the spouse or child." This is merely an opportunity for plaintiffs' attorneys to exploit and an invitation for frivolous litigation. There is no reason, in law or science, to provide statutory status for 4th cousins thrice removed, or the unknown relatives of the unknown biological father of an adopted child.

Inconsistent recordkeeping and technical requirements

H.R. 493 would require employers to follow one set of rules for handling genetic information and a different set for handling health care information. As a result, employers would have to distinguish between genetic information and other health care information they collect in the course of providing benefits, accommodations for the disabled, and a safe workplace, in general. Indeed, in many cases, employers might be required to keep two or more sets of confidential health care files for employees—one for records with genetic information, one for records with other health care information, one for insurance matters.

Further, making the distinction between genetic information and health information is not a task for laymen. Making that distinction, as demanded by the bill, may not even be possible. HR professionals should not be compelled to decide when a health problem is genetic or not, contingent or manifest, or any other similar decisions. As significantly, such decisions, if erroneous, should not be the basis of statutory claims, jury trials, and punitive and compensatory damages.

The balance of our submission is a discussion of existing state and federal laws which have a bearing on genetic discrimination in the workplace, and specific concerns with pending federal legislation. We believe they support the Coalition's belief that the current absence of claims of genetic discrimination in employment grows that the fact that (1) employers have no interest in acquiring such data and (2) current laws already prohibit and punish such conduct. That, in turn, supports the Coalition's belief that Congress faces no urgent need to act and can duly deliberate the implications of this or any legislation regarding genetic discrimination in the workplace.

*Current laws relating to genetic nondiscrimination**A. State laws*

State legislatures have been the pioneers in enacting laws governing various aspects of genetic information in the workplace. To date, laws enacted in over 30 states address in one form or another the issue of genetic discrimination in employment. In addition, other state laws may address additional select aspects of genetic information.

The state experience is valuable for a number of reasons. Not least of these is that it shows the 'cost' of hasty legislation in a rapidly developing area. No fewer than six states have already had to revise their laws to keep pace with scientific advances. More than any other feature of state law, this promises to be model for federal legislation.

The 1948 McCarran-Ferguson Act explicitly grants insurance regulation to the states. The Employee Retirement Income Security Act of 1974 ("ERISA ") preempts state laws pertaining to self-funded employee benefits plans. In 1996, the Health Insurance Portability and Accountability Act ("HIPPA ") became the first federal law to directly address genetic information. The law prohibits health insurance discrimination based on any "health status-related factor," including genetic information, for group health plans. Laws governing genetic discrimination in 34 states have complemented HIPPA protections related to health insurance.

B. Executive Order 13145

On February 8, 2000, President Clinton signed Executive Order 13145, which prohibits discrimination in federal employment on the basis of genetic information. The EEOC was assigned responsibility for the Executive Order and its enforcement under the Americans with Disabilities Act. On July 26, 2000, the EEOC issued a Policy Guidance explaining the definitions, Prohibitions, and exceptions in Executive Order 13145.

C. Title VII of the Civil Rights Act of 1964

Title VII of the 1964 Civil Rights Act may provide some protection against genetic discrimination where such discrimination may have "disparate impact" based on race, sex, religion or national origin, e.g., sickle cell anemia (African-Americans), Tay Sachs (Ashkenazi Jews).

D. Genetic information and the Americans with Disabilities Act

State and federal statutes prohibiting disability discrimination in employment are the most likely source of genetic information protections. The ADA protects individuals with one or more physical or mental impairments that substantially limits the individual in performing a major life activity; an individual with a record of such impairment; or an individual who is "regarded as" having such an impairment. It is clear that the ADA covers individuals who have a genetically-related disability once it is manifest and substantially limits a major life activity. Also, the ADA covers individuals with a prior record of a genetically-related disability that is manifest. However, the courts have not yet determined definitively whether the ADA should be construed to cover employment discrimination on the basis of genetic information concerning diagnosed, but asymptomatic, genetic conditions which are not manifest. To this point, virtually no case law exists regarding ADA coverage of genetic discrimination in the workplace.

That being said, the EEOC has long taken the position that the Americans with Disabilities Act protects individuals with asymptomatic genetic conditions from discrimination in employment. The EEOC successfully filed against Burlington Northern-Santa Fe Railroad based on genetic testing of employees for a genetic marker related to carpal tunnel syndrome. The notoriety of that incident demonstrates that it was a unique event. It also demonstrates that current laws were able to resolve the matter completely. After swift government enforcement actions, the parties reached a settlement on the EEOC suit in April 2001, in which the railroad agreed to stop testing. As was stated before the House on July 24, 2001 by one of those improperly tested by Burlington-Northern, the EEOC's actions were exceptional, effective, and exemplary.

Given the EEOC's guidance on this issue, as well as their enforcement history, employers should expect EEOC enforcement actions and individual charges under the "regarded as" prong of the ADA, if they choose to make employment decisions involving individuals with genetic disorders based upon myths, fears, or stereotypes, rather upon the person's ability to perform specific required job tasks, with or without reasonable accommodation, in a safe manner.⁴

Limitations on genetic testing in the workplace

An employer's ability to engage in genetic testing and to use the results of such testing in making a variety of employment decisions may already be limited in a number of ways by the provisions of the Americans with Disabilities Act. 42 U.S.C. Sec. 12101, et seq. Genetic testing is a medical examination and the ADA contains specific provisions limiting the manner in which an employer may conduct medical examinations and inquiries.

The ADA contains specific provisions dealing with the ability of an employer to request or obtain medical information or to require medical examinations. The ADA prohibits absolutely any medical inquiries or medical examinations at the pre-offer stage of the employment application process. 42 U.S.C. Sec. 12112(d)(2)(A). Genetic screening clearly constitutes a medical inquiry or examination and, hence, the ADA would prohibit an employer, for example, from requiring all job applicants to undergo genetic screening.

Once an offer of employment has been made, the employer may condition Sec. 12112(d)(3). This so-called conditional offer medical examination specifically is authorized under the ADA and the statute contains no limitations upon the scope of such an examination. Hence, the ADA, at this stage of the employment process, would not prohibit or limit the ability of an employer to engage in genetic screening. To give a conditional offer examination, however, an employer must satisfy three requirements. First, the examination must be given to all entering employees regardless of disability. Id. at Sec. 12112(d)(3)(A). Second, the information obtained must be collected and maintained in a confidential manner. 42 U.S.C. Sec. 12112(d)(3)(B).⁵ Third, the statute requires that the results of any medical examination may be used only in accordance with the non-discrimination requirements of the statute. Id. Sec. 12112(d)(3)(C). Generally, this requirement means that an employer may revoke a conditional offer of employment only if the results of the medical examination demonstrate that the individual cannot perform the essential functions of the job with or without reasonable accommodation.

Finally, the ADA limits an employer's ability to conduct medical examinations or make medical inquiries of current employees to those circumstances where the examination or inquiry can be shown to be "job related and consistent with business necessity." 42 U.S.C. Sec. 12112(b)(4)(A). This standard has been interpreted by the EEOC as relating to an employee's present ability to perform the job. See 29 C.F.R. App. Sec. 1630.10 (there should be "a fit between job criteria and an applicant's (or employee's) actual ability to do the job. "). Because genetic testing normally addresses what may occur in the future, not an individual's actual ability to perform specific job tasks, in most cases, it is unlikely the ADA would allow genetic testing of current employees under the "job relatedness" standard.⁶

The current trend of judicial decisions recognizes that non-disabled individuals may enforce the statute's restrictions on medical inquiries.⁷ Hence, even if an individual with a genetic marker or defect is not deemed to be "disabled" within the definition of the ADA, the statute still protects the person from being required to undergo genetic testing unless the testing complies with the above requirements.

Conclusion

In closing, the Genetic Information Nondiscrimination in Employment Coalition believes that genetic discrimination is wrong. To reiterate, we believe that employment decisions should be based on an individual's qualifications and ability to perform a job, not on the basis of characteristics that have no bearing on job performance.

The GINE Coalition believes that any federal legislation prohibiting genetic discrimination in employment should focus on controlling discriminatory conduct, not the flow of information, should conform to other federal employment discrimination laws, should create a single federal standard, should avoid duplicative administrative burdens, and should not impede the beneficent results of the remarkable research now taking place. Finally, such legislation should not be so broadly constructed as to encourage frivolous litigation. By acknowledging the principles set forth in this testimony, the subcommittee can help make this legislation more effective.

Again, I thank the subcommittee for listening to our perspective on the issue of genetic discrimination and for its invitation to testify today. The Coalition looks forward to working with you—in the future, as in the past—to make this the best possible law. I will be happy to answer any questions you may have.

ENDNOTES

¹Title 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.

²EEOC v. Burlington Northern Santa Fe Railroad (N.D. Ia, settled April 18, 2001).

³"[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)

⁴We 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 poses a "direct threat" to the health or safety of others in the workplace. 42 U.S.C. Sec. 12113(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.

⁵The 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.

42 U.S.C. Sec. 12112(d)(3)(B)(i)-(iii).

⁶An 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).

⁷See *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.]



*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>