GENETIC NONDISCRIMINATION: IMPLICATIONS FOR EMPLOYERS AND EMPLOYEES

HEARING

BEFORE THE

SUBCOMMITTEE ON EMPLOYER-EMPLOYEE RELATIONS

OF THE

COMMITTEE ON EDUCATION AND THE WORKFORCE

HOUSE OF REPRESENTATIVES

ONE HUNDRED SEVENTH CONGRESS

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GENETIC NONDISCRIMINATION:

IMPLICATIONS FOR EMPLOYERS AND EMPLOYEES

Tuesday, July 24, 2001

Subcommittee on Employer-Employee Relations

Committee on Education and the Workforce

U.S. House of Representatives

Washington, D.C.

The Subcommittee met, pursuant to call, at 2:00 p.m., in Room 2175, Rayburn House Office Building, Hon. Sam Johnson, Chairman of the Subcommittee, presiding.

Present: Representatives Johnson, Andrews, Fletcher, Hoekstra, Tiberi, Payne, Kildee, Rivers, McCarthy and Tierney.

Also Present: Representative Osborne.

Staff Present: Kristin Fitzgerald, Professional Staff Member; David Connolly, Jr., Professional Staff Member; Dave Thomas, Legislative Assistant; Paula Nowakowski, Staff Director; Peter Gunas, Director of Workforce Policy; Jo-Marie St. Martin, General Counsel; Heather Valentine, Press Secretary; Scott Galupo, Communications Specialist; Patrick Lyden, Professional Staff Member; Deborah L. Samantar, Committee Clerk/Intern Coordinator; Cheryl Johnson, Minority Counsel; Peter Rutledge, Minority Senior Legislative Associate/Labor; and Brian Compagnone, Minority Staff Assistant/Labor.

Chairman Johnson. The Subcommittee on Employer-Employee Relations will come to order. We welcome Mr. Osborne from our Education Subcommittees who joins us today.

We are meeting to hear testimony on genetic nondiscrimination and how it will impact employers and employees in the future. I am going to limit the opening statements to the Chairman and Ranking Minority Member. If other Members have statements they will be included in the hearing record.

With that, I ask unanimous consent for the record to remain open for 14 days to allow Members' statements and other extraneous material referenced during the hearing to be submitted in the official hearing. Without objection, so ordered.

OPENING STATEMENT OF CHAIRMAN SAM JOHNSON, SUBCOMMITTEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE

Good afternoon to all of you. Thank you for being here. Welcome to our Ranking Member Mr. Andrews.

Today's hearing focuses on genetic nondiscrimination and its implications for employers and employees. As you all know, genetic nondiscrimination is an issue because of the potential for private genetic information to be used in inappropriate circumstances. Often cited examples include those in which knowledge of a specific disease, cancer, for example, in an individual's family history would be used to discriminate against the individual in hiring.

With that said, let me make it clear that the Members of this Subcommittee are strongly opposed to genetic discrimination. Employment decisions should always be based on a potential employee's qualifications and the ability to do the job, not on factors, genetic or otherwise, that have no bearing on job performance.

Last year researchers at the National Institutes of Health announced that they had successfully completed a rough map of the human genome. This made possible a whole new universe of scientific discovery; one that we hope will contribute to the prevention and cure of human disease. The announcement also spurred a public policy debate about genetic information and what specific protection should be accorded to this new universe of information. Several existing Federal laws govern the privacy and use of genetic information and the protection of discrimination because of genetic factors. In addition, more than half of the States in the United States have enacted laws that further restrict the use of genetic information in health insurance underwriting and employment decisions.

This Subcommittee has jurisdiction over both the employer-provided health insurance and employment aspects of the genetic nondiscrimination issue. This is our first hearing on the issue intended to look at current employment law, State laws that impact the issue, current employment practices, and implications of the issue for both

employers and employees. Today we hope to answer many questions on the issue including (1) the extent to which the current Americans with Disabilities Act and State law protect individuals with genetic predispositions toward illness from employment discrimination; (2) the extent to which genetic testing is practiced by employers; (3) legitimate uses of genetic screening and monitoring in the workplace to prevent damage from exposure to workplace hazards; (4) enforcement mechanisms and penalties, including additional liability which is most applicable to this situation; and (5) the unintended consequences of overly broad definitions of genetic information and testing.

This is the first in a series of hearings, and we expect to follow this hearing with others to address the health insurance and Federal legislative aspects of genetic discrimination. I look forward to working my colleagues on the Subcommittee to address these issues.

WRITTEN OPENING STATEMENT OF CHAIRMAN SAM JOHNSON, SUBCOMMITTEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE – SEE APPENDIX A

Chairman Johnson. Right now I would like to acknowledge my colleague, Mr. Andrews, for his opening statement, and then we will look forward to welcoming our witnesses and their testimony.

Mr. Andrews.

STATEMENT OF RANKING MEMBER ROBERT ANDREWS, SUBCOMMITTEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE

I thank the Chairman. I thank my colleagues. I commend the Chairman for his continued good stewardship of this Committee in leading us to examine important issues of the day and always doing so in a fair and evenhanded way. I appreciate his cooperation, and I look forward to hearing what our witnesses will say.

We are living in a time of such dramatic change that it is difficult to keep up with it. I am privileged to be the father of an 8-year-old and a 6-year-old, and I really believe that during their lifetimes, when they are in a position to become parents, that they are going to be able to receive a genetic map of their children probably before the children are born, and be able to embark on a course of care that will dramatically reduce or even eliminate the prospect of many conditions and serious diseases that have plagued us as human beings throughout human history. It is an astonishing set of possibilities. It is an exhilarating set of possibilities.

With every set of possibilities comes a new set of risks, and this afternoon we are going to be asking some questions that did not even exist when I was privileged to come

to Congress 11 years ago. Frankly, it wasn't very relevant to think about an employer or an insurer getting access to genetic information about people 11 years ago because it wouldn't really tell them very much. It is going to become exceedingly relevant. In some cases it has already become exceedingly relevant. And I think we start these hearings from a point of consensus that Chairman Johnson stated a few minutes ago, and that is, in this society, and in this economy, how far you go in your chosen profession should be a function of your ability and your desire, not a function of your race, your gender, or some other immutable characteristic about your person.

Your genetic structure is obviously the most immutable characteristic about your person. A few years ago in this Congress, we had a debate about whether or not insurance companies should be able to deny health insurance based upon a preexisting condition. Well, now the debate has taken a dramatic leap because the debate is about whether insurance companies should be able to deny coverage based upon the probability of a preexisting condition, not the manifestation of one. We have had discussions over the years about whether certain personal characteristics should be protected under the employment discrimination laws, obesity, alcoholism, and various other conditions. Well, we are now going to have a debate about whether the probability of these conditions manifesting themselves can give rise to any form of employment discrimination.

What is refreshing about this debate is that it is so early in the game that the usual ideological divisions have not yet formed, because not only do we not know how we feel about the answers, we are not sure we even know all the questions. I think that this afternoon is an excellent starting point for us to begin to formulate those questions. I start from the principle that if my grandchildren, someday are able to be protected against the ravages of diseases because of knowledge of their genetic structure, I also want to be sure that the law protects them against limitation of their personal opportunities based upon that very same genetic structure. I want their future to be based upon their intellect, their work ethic, their values, and not upon their DNA.

I think that's an excellent place for us to start. I look forward to hearing from the witnesses and thank the Chairman for calling this hearing.

Chairman Johnson. Thank you, Mr. Andrews.

It is now my pleasure to introduce our panel of witnesses. The first witness on the panel is Mr. Cheye Calvo, Senior Policy Specialist for the Employment and Insurance Program, National Conference of State Legislatures. I used to belong to that organization. Thank you for being here.

I am going to yield now to my colleague and friend from Nebraska Mr. Osborne, who will introduce our second witness.

Mr. Osborne. Thank you, Mr. Chairman.

It is my pleasure to introduce Mr. Gary Avary, accompanied by his wife Janice, from Alma, Nebraska, which is in my District. Gary has worked for Burlington Railroad for 27 years. Janice works as a nurse. We are very pleased that they would take time to

come all the way to Washington to testify at this hearing.

Chairman Johnson. Thank you, Mr. Osborne.

Mr. Osborne. Thank you, Mr. Chairman.

Chairman Johnson. We appreciate you being here as well.

Following Mr. Avary will be Mr. Eric Greenberg, Director of Management Studies for the American Management Association. And our final witness for today will be Mr. Harold Coxson, Partner at the law firm of Ogletree, Deakins, Nash, Smoak, and Stewart. He is testifying on behalf of the Genetic Information Nondiscrimination in Employment (GINE) Coalition. That's a mouthful, isn't it?

Let me remind the witnesses that under our Committee rules, they must limit their oral statements to 5 minutes. We wish you would observe that. Your entire written statement will appear in the record. The lights in front of you are green, and will turn yellow at 1 minute, and red when 5 minutes is up.

Mr. Calvo, you may begin your testimony now.

STATEMENT OF CHEYE CALVO, SENIOR POLICY SPECIALIST FOR THE EMPLOYMENT AND INSURANCE PROGRAM, NATIONAL CONFERENCE OF STATE LEGISLATURES, DENVER, CO

Chairman Johnson and Members of the Subcommittee, it is a pleasure to be here. I am Cheye Calvo, an employment and insurance policy specialist with the National Conference of State Legislatures. NCSL is the bipartisan national organization representing the Nation's 7,424 State lawmakers and their staff from all 50 States, the commonwealths and the territories. We include active Members from many States as well as Members on this Subcommittee, including Speaker Pete Laney of Texas and Senate President Joe Schwarz of Michigan.

NCSL does not take positions on matters internal to the States and has not taken an official position on Federal proposals to address genetic information in the workplace. I am here today to share with you what the States are doing on this issue and frame the State legislatures debate for regulating the genetic information in the workplace.

Human genetic technologies may prove the defining scientific advancement of the 21st century. Yet concern over misuse by employers, health insurers and others with financial interests in genetic information have led State legislators to act. States now have a decade of experience crafting public policy for genetic technology. In short, State lawmakers have learned that genetic policy is difficult, complex and in need of regular review to keep up with the ever-changing nature of the science. Still, State lawmakers have tackled these challenges to make genetics one of the most active State legislative

issues of the last 10 years.

States have attempted to guide genetic technologies, not to control them. In turn, State genetics protections are designed as preventive measures to guard against misuse before it becomes widespread and promote the use of genetic advances to extend, enhance and save lives. But State legislators also recognize they are working in uncharted territory by setting policy for technologies that are only beginning to take shape. Therefore, they foresee the need to regularly review State laws to account for the rapidly changing science and to guard against unintended consequences.

That said laws in 28 States, including six enacted this year, address the use of genetic information in the workplace. Forty-eight States also have State disability protections that, like the ADA, may apply. All of these laws center around two related but distinct issues: first, employers' use of genetic information; and, second, genetic testing and inquiries in the workplace. Key policy considerations include approaches to genetic protections, the scope of genetic protections, general exceptions and enforcement provisions.

The central policy issue is whether genetic information is special and requires higher legal protections or whether it is simply another form of health information and should be treated the same. The answer to this question largely influences the policy approach. The ADA allows employers to condition job offers on the completion of medical exams and to conduct medical testing and inquiries of current employees that are job-related. Therefore, an inclusive approach to genetic employment policy, based on the ADA, permits some degree of genetic testing. Genetic-specific laws place greater restrictions on employers' use of genetic information and may include strict bans on the use of genetic testing by employers.

Twenty-six States have taken the exceptional approach to genetic information protections. Such laws may include adding genetic information to the list of other unlawful employment criteria, such as race or gender, or establishing entirely new bodies of law.

An inclusive approach may incorporate genetic testing standards either implicitly or explicitly into current workplace disabilities protections, as has been done in Michigan and Illinois. Many also advocate that policymakers bolster disability protections or establish broader measures based on future or current health status. California and Minnesota to some degree have moved in this direction.

The second principle consideration relates to the scope of genetic protections. Scientists fail to recognize an absolute delineation between genetic and other health information. Therefore, laws must clearly define the realm of protections. All State genetic laws protect the results of genetic tests, but many extend to other elements, such as information about genetic testing or services, the test results of family members, family history, and even inherited characteristics. Nine State laws exclusively cover predictive genetic information, while others extend to diagnostic tests, or genetic testing of any kind.

Regarding general exceptions, most State laws establish instances where genetic protections do not apply. The most common relate to employees that, due to a medical condition, are unable to perform essential job functions. Others allow exclusions if related to health or safety, to determine an employee's susceptibility to toxic exposure or to investigate a worker's compensation claim.

Finally, most States enforce genetic employment laws through the same mechanisms that they assign for other unlawful employment practices. The primary method of enforcement is through private rights of action following an administrative review and fact-finding by the State agency or EEOC. Several States, however, provide for special specific civil liabilities, administrative fines and criminal penalties for violators of genetic protections.

In conclusion, State lawmakers have been proactive in shaping an initial layer of public policy to govern genetic information in the workplace, yet they recognize that they will be called upon to revisit State genetic laws in the years ahead as the technologies continue to advance.

Thank you for this opportunity. I am pleased to answer any questions.

WRITTEN STATEMENT OF CHEYE CALVO, SENIOR POLICY SPECIALIST FOR THE EMPLOYMENT AND INSURANCE PROGRAM, NATIONAL CONFERENCE OF STATE LEGISLATURES, DENVER, CO – SEE APPENDIX B

Chairman Johnson. Thank you. We appreciate your testimony.

Mr. Avary, you may begin your testimony. Thank you.

STATEMENT OF GARY AVARY, EMPLOYEE, BURLINGTON NORTHERN SANTA FE RAILROAD COMPANY, ALMA, NE

Good afternoon. Thank you for inviting me to testify at this Subcommittee hearing. My name is Gary Avary, and this is my wife Janice Avary. I am from Alma, Nebraska, population 1,200. I am 45 years old and have been married for 28 years. Janice and I have three daughters and one grandson. I have worked for Burlington Northern Santa Fe for 27 years in the track and maintenance department. And I am a 27-year member of the Brotherhood of Maintenance of Way Employees union.

In September 2000, after working on several derailments over a short period of time, I started having pain and numbness in my right hand, specifically in the fingertips. This made it very difficult to do many aspects of my job safely, since derailment repairs require continuous hours of using high-impact vibrating tools. On September 13, I saw a hand-shoulder-arm specialist and had extensive tests done. I was diagnosed with carpal tunnel syndrome. This is a swelling and a scarring of the tunnel in the wrist that carries

the nerve to the hand. This CTS is caused by extreme temperature changes and continuous repetitive activity. About a week later the railroad authorized surgery, and on September 28 I had laparoscopic repair done. Three weeks later I was back to work with 100 percent use of my hand.

On October 24, the railroad medical department requested all of my medical records pertaining to my CTS exam and surgery to further evaluate workplace responsibility. During this time my medical insurance paid for the surgery, and the BNSF paid all expenses not covered by insurance plans. In December I received a registered letter from the company notifying me of a required mandatory medical exam, which would include X-ray, nerve test and laboratory tests.

When my wife and I found out from a coworker that as part of the test the lab took seven vials of blood, we started questioning. My wife is a registered nurse. She started making phone calls to find out what these tests were and was told accidentally that a genetic test would be included. An appointment coordinator, a secretary and the chief medical officer of BNSF told my wife that this exam was mandatory, according to a corporate internal rule 26-3, regarding mandatory medical exams. By not going to this exam I would be considered an insubordinate employee and fired.

My wife contacted a FELA attorney, who represents the Brotherhood of Maintenance of Way union members, to see if this was legal. It was not. Then we contacted the EEOC for job protection for me. I am more fortunate than most people in the workplace because I had a union to support and protect and guide me through this.

I didn't go to the company-required doctor's appointment on January 25, 2001, so, in turn, the railroad notified me by registered letter that my behavior was under disciplinary investigation and set a date for the hearing on this matter. If you work for Burlington Northern Santa Fe, you know this means that you will be fired. After attempts by the union to cancel this investigation, the railroad changed the date, but did not cancel the hearing until the EEOC and a Federal judge ordered them to do so. I still work for Burlington Northern Santa Fe under the protection of EEOC Whistle-Blowers Act.

Since this began, my wife and I have been doing extensive research into the issue of genetic discrimination. We have talked to individuals from all over the U.S. who have lost their jobs and/or insurance coverage because of actual or potential diseases.

We are strong supporters of H.R. 602 and S. 318 introduced by Congresswoman Louise Slaughter and Senator Tom Daschle respectively. They have been trying to get genetic discrimination protection passed for 5 years. This type of discrimination has been happening all along, but no one wanted to believe it. A law that protects all Federal employees from this type of testing and discrimination was passed during the Clinton administration.

I think it is time that all Americans are protected from this type of mandatory testing and discrimination. What happened to me should not happen to anyone, especially in the United States. It is a direct infringement on our fundamental rights to be who we are. No one can help how we are put together. Only God knows that. The

employer, the insurance company or anyone else has no business with that knowledge. That information should be shared only if you voluntarily request the testing. Then it can be used to your benefit. It should not be used against you and your family for hiring and firing practices or acceptance and/or denial into insurance programs.

Please help us get strict Federal laws passed so that this type of testing and discrimination can't happen to anyone else in the future. Thank you.

WRITTEN STATEMENT OF GARY AVARY, EMPLOYE, BURLINGTON NORTHERN SANTA FE RAILROAD COMPANY, ALMA, NE – SEE APPENDIX C

Chairman Johnson. Thank you, sir.

Mr. Greenberg, you may begin your testimony.

STATEMENT OF ERIC GREENBERG, DIRECTOR OF MANAGEMENT STUDIES, AMERICAN MANAGEMENT ASSOCIATION, NEW YORK, NY

Thank you, Mr. Chairman. The American Management Association and its Board of Trustees appreciate this opportunity to share with the Subcommittee the results of our research into workplace medical testing in general, and genetic in particular. The AMA is not a trade association, and our charter prohibits us from lobbying for legislation, but as a part of our core mission of management development and training, we perform surveys on a variety of management issues, establishing benchmarks and assisting the management community in policy development and implementation.

The AMA launched its first medically related survey in 1987. Over the years we have revised and expanded the questionnaire, most recently in 1997, when for the first time we asked about genetic testing. In brief, what we found that year and in subsequent years was that genetic testing is rare in corporate America, and that it is not well understood by the human resources managers who complete our annual questionnaire. And I do want to emphasize that it is human resources managers, not medical officers or risk management officers, who fill out and return our questionnaire.

We have found a great deal of testing for illegal substances, somewhat lesser testing for fitness for duty, and practically no testing for inheritable diseases. Among the few companies that perform such testing, an even smaller number say they use the test results in determining whether to hire or not to hire employees, or to assign or dismiss current employees.

Specifically about genetic testing, we listed that phrase, "genetic testing," among 10 forms of medical testing in our 1997 questionnaire, and when the results came back

from 906 AMA member and client organizations, 52 companies, or 5.6 percent of those surveyed, had checked the box that indicated that they performed genetic testing. We had no particular reason to doubt that figure. The only previous survey of which we knew, performed in 1989 by the Office of Technology Assessment on a much smaller scale, also found about 5 percent performing genetic testing, but because we had no baseline data from previous years, we did not make our 1997 finding public.

In 1998, we found an almost identical share of respondents, 5.2 percent or 56 companies out of that year's sample, indicating that they performed genetic testing. Again, there was no particular reason to doubt the finding, but we were and are aware that this is a particularly sensitive issue, and we wanted to be sure we were right before we publicly released the finding, and so we put our researchers on the phone to every human resources manager we could contact who had indicated to us that their companies performed genetic testing. We reached 44 of them and found that 80 percent of them did not perform genetic testing in any way, shape or form.

Under follow-up questioning, many HR managers told us that they considered any blood tests to be a genetic test. Others thought the testing for the presence of a disease, as opposed to a genetic susceptibility, was a genetic test. No more than nine companies, less than 1 percent of the 1,085 in that year's sample, did anything that might qualify as a genetic test. Unanimously, the companies that did genetic tests told us that they performed them for no other reason than concerns over workplace safety and health.

The next year, 1999, we took genetic testing out of that matrix, that list of 10 forms of medical questioning, and from Barbara Fuller, the Human Genome Project of the National Institutes of Health, we received a definition of genetic testing, and we printed it in a separate box in our questionnaire. And under that definition we said according to this definition, do you perform genetic testing on job applicants or current employees? That year, 1999, first year in which we used this format, only 3 companies out of 1,005_ 4 checked yes. In the year 2000, 7 companies out of a much larger sample of 2,133; and this year, 2001, 2 companies out of 1,627 surveyed checked that box indicating that they performed genetic testing.

If genetic testing is being done to any appreciable degree among AMA membership and client base that together employ about one-fourth of the American work force, we haven't been able to find it. It must be admitted, however, that if companies were using such testing for nefarious reasons, they would be unlikely to report it in an AMA survey.

Genetic testing is another tool that modern technology has placed in our hands with a potential to be used for good or ill. It is easy to create nightmare scenarios in which people are judged not by their abilities, but instead by genetic propensities and susceptibilities, and indeed Hollywood has already done that. But human resource managers in major US firms have to deal with reality and not fantasy, and insofar as AMA's research can tell, the reality is as stated. Genetic testing is rare. Where done, it is performed with the health and safety of workers foremost in mind, and it is widely misunderstood. And for the record, Mr. Chairman I furnished to the Subcommittee a summary of AMA's 2001 Survey of Medical Testing. Thank you.

WRITTEN STATEMENT OF ERIC GREENBERG, DIRECTOR OF MANGEMENT STUDIES, AMERICAN MANAGEMENT ASOCIATION, NEW YORK, NY – SEE APPENDIX D

Chairman Johnson. Thank you. We will put that in the record.

Our final witness is Mr. Coxson.

STATEMENT OF HAROLD P. COXSON, ESQ., PARTNER, OGLETREE, DEAKINS, NASH, SMOAK, AND STEWART, WASHINGTON, D.C., ON BEHALF OF GENETIC INFORMATION NONDISCRIMINATION IN EMPLOYMENT (GINE) COALITION

Thank you, Mr. Chairman, Mr. Andrews and the Members of the Subcommittee. I represent the Genetic Information Nondiscrimination in Employment Coalition, the acronym GINE Coalition, which is why the long name to get to that acronym. We appreciate the opportunity to appear before this Subcommittee.

During the debate on the Americans with Disabilities Act, and many of you may remember and have participated, of course, in that debate, will you recall that Justin Dart and others from the disability community were heard to say, "we are the disabled." "You", meaning others in society, "are the yet to be disabled."

The subject of today's hearing underscores that message. According to geneticists, we each carry at least three defective genes. Two-thirds of us will die for reasons connected to our genetic makeup.

We are all, every human being, born or yet to be born, all of us, members of the protected class defined by genetic predisposition to disabling conditions, which, of course, makes us all potential litigants under legislation proposed or to be proposed in this Congress, whether or not we ever become actually disabled. Yet despite this unlimited class, no empirical evidence of widespread employment discrimination based on genetic information exists.

Despite 28 State laws, some on the books for over a decade, few, if any, charges or reported cases have been found. Despite the EEOC's 1995 interpretation that the Americans with Disabilities Act already prohibits discrimination against workers based on genetic makeup, there have been only a tiny handful of charges filed anywhere in the Nation with the EEOC, and where there was a highly publicized charge filed, in the Burlington Northern Santa Fe Railroad case, EEOC took swift and effective action under the Americans with Disabilities Act.

I know that case is cited as a reason why this legislation or why legislation is necessary. I think it also argues why perhaps the current law works with respect to

genetic information discrimination. As contrasted with the mountains of evidence of discriminatory conduct, which preceded passage of Title VII of the Age Discrimination in Employment Act and the Americans with disabilities Act, there is no empirical evidence of widespread genetic discrimination.

The AMA and Society for Human Resource Management surveys indicate that rarely do employers require genetic tests or base employment decisions on genetic information. The reason: The predictive ability of genetic tests and other forms of genetic information has little practical workplace utility. There is no medical certainty that a condition will ever occur, or, if it does, when in the future, 5, 10, 15, 20 years from now, and it is simply too remote and currently too speculative on which to base employment decisions.

So, if there is no widespread testing or use of genetic information in the workplace, and there is no evidence of widespread employment discrimination, and the ADA and State laws already cover genetic discrimination, why make Congressional action or Congressional attention be necessary? Well, one answer is that the EEOC's interpretation has not been tested in the courts. Another answer is that remedies, according to proponents of legislation, should be created that are far greater for victims of genetic discrimination than for victims of any other employment discrimination. And also, testing requirements perhaps need to be strengthened under the Americans with Disabilities Act. But I think the best answer is to advance medical science, because there is, in fact, a very real fear on the part of employees that genetic discrimination will occur based on this information.

We have attached to our testimony copies of the GINE Coalitions principles, and I won't elaborate on all of them in my oral remarks today because I can see that my time is expiring. However, I think that it is safe to say that the GINE Coalition is supportive of a dialogue on this and is supportive of working with members of this Committee, and the Administration. And we note that the President has recently endorsed legislation that would be fair, reasonable and consistent with existing laws.

The final point I want to make regards consistency. We feel, for example, that there is no reason why those alleging discrimination based on genetic information should be entitled to greater rights or protections than individuals alleging employment discrimination on the basis of race, sex, religion and national origin or age. It makes no sense logically, legally or equitably for asymptomatic individuals not currently, and hopefully never, disabled to receive greater rights and be entitled to greater damages, such as unlimited punitive and compensatory damages, than those currently available for disabled individuals under the Americans with Disabilities Act.

I thank you for your attention, and I will be happy to respond to any questions.

WRITTEN STATEMENT OF HAROLD P. COXSON, ESQ., PARTNER, OGLETREE, DEAKINS, NASH, SMOAK, AND STEWART, ON BEHALF OF GENETIC INFORMATION NONDISCRIMINATION IN EMPLOYMENT (GINE) COALITION
SEE APPENDIX E

Chairman Johnson. Thank you, sir. Thank you all for your testimony.

Mr. Coxson, you just made the statement that there should be no greater entitlement to rights or protection than any individual alleging discrimination on the basis of race, sex, religion or national origin, and that, as with other forms of employment discrimination, allegations of genetic discrimination should be required to be the subject of investigation and other procedures of the EEOC. How do currently sponsored legislative proposals depart from this standard, or do they in any way?

Mr. Coxson. They do depart, Mr. Chairman. They are a form of what we would call genetic "exceptionalism" because they provide for unlimited punitive and compensatory damages. As the Chairman knows, there are caps on damages under the Americans with Disabilities Act and other forms of discrimination against other protected classes under Title VII.

Also, the current legislation bypasses, or circumvents the administrative remedies and the administrative investigatory and mediation process of the EEOC. It provides for a direct access to court, although it provides an alternative route, going through EEOC.

Our coalition thinks that like all other forms of employment discrimination, the processes of the EEOC can be beneficial in screening and resolving cases at an early stage outside of court. Therefore, those processes should be availed for genetic discrimination as they are under the current interpretation of the EEOC of the Americans with Disabilities Act.

Chairman Johnson. Now, there are protections against total lawyer involvement here if we use EEOC as a base; is that true? In other words, the main difficulty that I see here is broadening it to the point where we are going to have a lawyer protection act instead of protecting the rights of the individual if we are not careful.

Mr. Coxson. Well, Mr. Chairman, the statistics from the EEOC indicate that with respect to all other forms of discrimination that come before that agency, in fiscal year 2000, only 8.8 percent of all the charges filed were found to have reasonable cause, 58.3 percent had no reasonable cause, and 20.5 percent involved administrative closure. Now, that is not to say that those individuals could not go into court and, in fact, receive a right to sue letter and go into court. But I think the statistics speak for themselves.

And by the way, that 8.8 percent number in fiscal year 2000 is an all-time high. If you look back over the past decade, those statistics have been in the 2 percent range; 2 percent of merit, 2 percent reasonable cause of the charges filed.

If, however, you bypass that procedure and allow people to go directly to court, you are going to inundate the courts with these types of charges, some of them frivolous, some of them meritorious. But you can eliminate a lot of that logjam through the administrative process of the EEOC.

Chairman Johnson. Thank you, sir. I appreciate those comments. I am going to cut my questioning short.

Mr. Andrews.

Mr. Andrews. Thank you, Mr. Chairman.

Let me first say to Mr. And Mrs. Avary, thank you for your attendance and testimony today. I am glad you are here, but I wish you were not. I wish that the circumstances that led up to you being here today had not occurred. I can only say I have great personal respect for what you have done. I think there is no greater gift we can give those three daughters and that grandchild of yours than showing them what integrity is and by being willing to see this through, I am sure at great personal cost. You have my respect, and I very much appreciate you being here to tell your story. I respect all the witnesses and appreciate all the testimony.

Mr. Coxson, I note you had the good sense to grow up in the area of the country that I represent, and I appreciate that. I want to ask you a couple of questions.

If I understand the coalition's position correctly, it is essentially that the existing complexion of employment discrimination laws get the job done, and we don't need some sort of exceptional prohibition on discrimination based upon genetic information; is that correct?

Mr. Coxson. It is correct to the extent that we think that genetic discrimination should not receive preferential treatment over other forms of discrimination. We think it should be covered. We support the current interpretation of the EEOC, which we believe covers genetic discrimination.

Mr. Andrews. Would you favor adding discrimination based upon genetic characterization as a protected class under the EEOC Title VII?

Mr. Coxson. That is an issue that we have not taken up in the Coalition, so I can't speak for the Coalition on that. I think that Title VII has, in fact, on rare occasions provided protections for genetic discrimination where the genetics are linked to a particular protected class.

Mr. Andrews. Tai-Sachs and sickle cell anemia are really religious and racial.

Here is the question that I am really getting at. If you take a set of facts like Mr. Avary's, let's say that an employer discharges an employee because the employer believes the employee is likely to have a heart attack based upon the employee's genetic profile. Is that decision prohibited under Title VII as it stands today? Would that be illegal?

Mr. Coxson. No. But it is protected under the Americans with Disabilities Act, the third prong of the definition of "disability" where someone is regarded as disabled. As Mr. Andrews knows, there are three prongs to the definition of a disability.

Mr. Andrews. Not to interrupt, I do understand. I have read that.

Would the Coalition favor an amendment to the ADA that would adopt the definition of disability that the EEOC has put forth with respect to this question?

Mr. Coxson. The Coalition would prefer an amendment to the ADA. We think that is the most straightforward route.

Mr. Andrews. I think that is what I just said. So the answer is yes.

Mr. Coxson. The answer is yes.

Mr. Andrews. So the Coalition would support importing the EEOC's guideline definition into the statute under the ADA.

Mr. Coxson. Because we feel it is already the EEOC's interpretation. So it is really codifying their existing interpretation.

Mr. Andrews. The only other point that I would make is that I understand the data about very few claims being presented in this area. I think that is because the technology is still in its early stages. We aspire to the day when a genetic profile will be easily attained, but we are certainly not there yet. So if the scientists cannot provide a comprehensive genetic snapshot of a person, then obviously employers are not going to be using that snapshot for any purpose because they don't have it yet. So I think the fact that the record is scarce with respect to these claims being filed is more a reflection of the infant stages of the technology than it is the unlikelihood that the technology would be used in a way that might discriminate. Would you agree with that?

Mr. Coxson. Well, Mr. Andrews, I would say that is also a reason why we should go cautiously in this area, because the technology is evolving so rapidly. Some States, for example, even though their laws have been on the books a decade, have had to revisit those laws already. They have had to revise them and amend them. And I would say that in this area, if there is going to be freestanding legislation, that freestanding legislation ought to be sunsetted, or there at least ought to be an opportunity for subsequent review. There may very well come a time, as you alluded to, when employers will want this information, and employees will want them to have the information for salutary purposes.

One of the concerns that we have with some of the existing proposals is that some of those salutary programs such as wellness programs that are employer-provided may be impeded as a result of legislation that would punish the flow of information and sanction the flow of information as opposed to discriminatory conduct. We think the focus should be on discriminatory conduct, not the flow of information.

Mr. Andrews. I see my time is up. I would just note for the record, though, that proving discriminatory conduct is very often difficult to do, and I would want to steer clear of a situation where the burden would be on the employee to demonstrate that conduct if, in fact, the opportunity to exploit the information was broadly available. I think having the information alone is an issue.

I yield back.

Chairman Johnson. Thank you, Mr. Andrews.

Mr. Calvo is there any one State that is further ahead than others on this issue?

Mr. Calvo. It is really not a matter of who is further ahead; it is a matter of experimentation. There are a wide range of State laws, and some States were enacting laws back in 1992. Wisconsin was the first. Others have acted more recently. Michigan, for one, went through a very detailed, comprehensive, deliberative process a couple of years ago and took a different approach from others. But there is a series of models that are in place in the States, and because we haven't seen the use of the information by employers right now, legislatures are still grappling with what the issues are. But we haven't seen the experience by employers and going through the process to really identify how effectively the laws will work once that technology is more available.

Chairman Johnson. It is evolving, isn't it? And you have made some statements that employers may have legitimate worry as the States begin to evolve what this legislation says. How have States protected employers' efforts to improve worker safety and be free from lawsuits that might be filed on a frivolous basis?

Mr. Calvo. Like the ADA, most State disability laws do require an administrative review. They require that if you are going to file a claim, you must first file it with the State agency and go through an administrative process, have a fact-finding session, and only after that process can you go to court. That remains the case in most States.

For genetic legislation there is an administrative process, but the laws themselves also incorporate a number of limitations. Some of them are sweeping, but most of them do incorporate some degree of exceptions. One that has been discussed most often is a genetic disposition that may, in fact, limit someone's ability to do a job that could be some sort of toxic exposure. Health and safety exceptions have been worked into a number of laws as well.

One of the major distinctions is in defining the explicit information you are protecting. All States protect predictive genetic information derived from predictive genetic tests. That is different than a diagnostic test that is used to identify whether or not someone has a current illness or condition. So that is probably the most common limitation as well. But some States, like I said, only address predictive genetic information, while some add in other components like family history. A few even go so far as to add inherited characteristics.

And so there is a wide variety. But most State laws do have some limitation worked into it, and they all, like I said, do require some sort of administrative process before going directly to trial.

Chairman Johnson. Thank you, sir.

Mr. Tiberi, do you wish to question?

Mr. Tiberi. Thank you, Mr. Chairman.

My question was also for Mr. Calvo. I am a creature of the State legislature. In fact, the Senate President Dick Finan has been very active in NCSL. One of the things he said to me after I was elected to Congress last November was, remember you came from the State legislature. Don't forget that. And I have noticed that Congress sometimes tends to forget that there are State legislatures out there.

Referencing your testimony, you mentioned that several States have had unintended consequences from the legislation that they have passed dealing with this issue. Can you touch on a few of those?

Mr. Calvo. I don't think in many cases we have seen unintended consequences yet. As the technology evolves over time, they are reviewing and reevaluating things that they have done.

Probably the most notable revision occurred this year. The State of Oregon, in 1995, passed a law that identified the rights of ownership of genetic information and DNA samples as the property of the individual from whom it is taken.

And there has been over the 6-year period a great deal of debate over linking genetic information with an existing body of law, like property, when dealing not only with statutory law but also common law, is in fact the right approach. This year, along with a number of other reforms, Oregon decided that that wasn't the best approach and actually repealed that law. The State decided there were other ways to reach the same protections.

I think one of the major issues here is we really don't know what this technology is going to do. All we have in front of us right now are a handful of single genetic markers that are linked to disease, but most disease isn't a single gene. It is a combination of 10, 20, 30 genes and environmental factors. And we are just scratching the surface as to exactly what information this technology is going to ultimately reveal.

So I think State legislators have been cautious and don't want to pass laws that are going to prevent potential benefits for the technology. They obviously want to resolve concerns, but prevent misuse. They want to make sure that if there are legitimate uses for this technology, that ultimately those technologies are put into place. Quite frankly, we would like to think that this technology will be available to actually prevent what might be otherwise unavoidable exposures and injuries in the workplace.

Mr. Tiberi. I have just one follow-up question, Mr. Chairman. If you were to give us a piece of advice as to how to proceed based upon your knowledge in your job and what you have seen in other States, what would the one key piece of advice be?

Mr. Calvo. Twenty-eight states have laws on the books that address these issues, and I think there is rich policy experience there. So I would encourage you to just look at what the States have done, and then reach your own conclusions.

Chairman Johnson. Thank you. We appreciate those answers.

Mrs. McCarthy, would you care to question?

Mrs. McCarthy. Yes. Thank you, Mr. Chairman, and thank you for holding this hearing.

Mr. Avary, I am curious. In your testimony you state that you found out by accident that your blood work was to be genetically tested. Did you ever find out why they were taking blood for genetic testing?

Mr. Avary. Well, they told me they were looking into the business necessity of it. If I were predisposed to carpal tunnel syndrome, they would actually put a weight-restricted limit on me someday that I couldn't perform my job; then they would eliminate me.

Mrs. McCarthy. Eliminate you?

Mr. Avary. Oh, yeah. They would eliminate me. Fired.

Mrs. McCarthy. One of the things that I am certainly curious about, and anyone can certainly try and answer my question. I am looking beyond what we are talking about here today. In the future with genetic testing, we will hopefully see many people take advantage of it. But going over all your papers one of the things I am concerned about is did you sign any kind of release to have genetic testing done on you?

Mr. Avary. No, ma'am. I didn't get that far. I opted not to sign anything, and that is where we stood our ground. Several other people did sign a consent to go give blood, but we did not.

Mrs. McCarthy. All right. This is what I think we are trying to determine; what kind of legislation we can pass to protect people. We certainly want to have people partake of genetic testing, and I think that is important. My concern is, especially since we are going to be doing the Patients' Bill of Rights either Thursday or Friday, is that any company that has health care insurance is going to start doing genetic testing. If somebody employs you, they will make you go through the genetic testing, and then are you going to be turned down by the insurance plan? I am looking at it that way.

I don't know if that really falls into the scope of what we are talking about today, but as a nurse, that to me is scary, because, as you said, each and every one of us has two or three defaults in our genetic makeup. I want research to hopefully find cures, not discriminate in hiring, and health care insurance. That is what we are trying to find out and prevent. Start now, maybe with limited language, but send a message that we are watching what is going on out there.

Would anyone like to comment?

Mr. Coxson. Mrs. McCarthy, I would point out that I think the situation you described may be covered under HIPAA. I don't know for sure, but I think it may be already prohibited or dealt with under HIPAA.

Mrs. McCarthy. We will look into it.

Mr. Coxson. I am referring to health insurance, obviously not employment discrimination.

Mr. Avary. I would like to add one more thing.

When you talk about opening the doors for lawsuits, it was a terrible thing that we couldn't have stopped this earlier. But when you have a company that uses an internal rule against you, where they say they have the right to compel testing without your consent, where do we stand? We stand in intimidation and fear of a corporation. When you go against an internal rule, it will lead to disciplinary action. Whether it is 30 days, 60 days, 90 days, whatever, they will hit you in the pocketbook.

Mrs. McCarthy. I think that is also one of the concerns that we have here. I will certainly look to see if patients are protected on this.

From what I understand in reading your testimony, you had a union to back you up. There are an awful lot of jobs throughout this country that don't have unions to back you up and fight for you. Where is the little guy going to go? The little guy is going to sign those papers and not even know what his or her rights are. So that is something else that we have to look into.

Mrs. Avary. That is why this was handled in that manner. The employees of that company had no idea when they were asked to go to this medical exam exactly what it entailed until they got to the doctor. That is where they may have signed a paper. As you know, when you go to the laboratory for any type of testing, you have to fill out paperwork giving permission that this information will be sent to your insurance company for payment. That is where these employees may have first signed for permission for them to have this blood work. But yet, in signing, it was probably not explicitly detailed that they were drawing seven vials of blood to genetically test. No, it was described as routine laboratory tests, which, to most people, are just common everyday testing.

What most people don't realize is that even routine testing requires some preparation for accurate test results. So when they were talking to me about the fact that it would be routine blood testing, I wondered why people weren't told to fast or given specific instructions to follow 24 hours before the testing? So were they actually curious and really wanted to know the results of these tests, or did they have something else in mind?

So the employee knew nothing when they went. They just knew that they were following rules set down by their employer; go see this specialist, and we will determine from that whether it is a workplace injury or not. And not only do they go one time, they are sent five or six times until they finally get to this blood testing.

Mrs. McCarthy. I thank you for that answer. Unfortunately, the majority of people are not married to nurses who know how to do the research, but we are working on that.

Mr. Calvo. A number of States have also passed explicit laws that require stronger informed consent provisions for genetic testing versus other types of medical testing. One of the big issues out there is that genetic testing may have more profound and significant implications. Therefore, a number of States, including Massachusetts, which I believe is where some of the tests in the Burlington case were performed, does have explicit written consent requirements that may or may not apply in this particular instance.

Chairman Johnson. Thank you, Mrs. McCarthy.

Mr. Fletcher, you may inquire.

Mr. Fletcher. Thank you, Mr. Chairman. I appreciate your holding this hearing. Medicine and technology seems to move ahead of legislation in a lot of areas.

Chairman Johnson. Are you going to add this to the Patients' Bill of Rights?

Mr. Fletcher. Actually we had a portion of it in there.

Chairman Johnson. I thought you might answer that way.

Mr. Fletcher. Once we started looking at the issue and realizing how complex it was, we didn't want to make it any more complex than it is. We think it is important for us to hear this. Changes in technology, protecting workers, and the privacy rights they have is very important.

We need to do it in a way that not only protects health, because there are some things that are predictive. We are already capable, for example, to do some things that are very important in colon cancer and breast cancer. And if there is a genetic test that proves very, very good on colon cancer, it is a disease that we can screen for, target and help prevent. So that is going to be very important to have. We do, however, need to strike a balance where we protect patients regarding discrimination, but we also need to protect them in screening to make sure we can help them both ways.

Let me direct this question to Mr. Coxson. I believe in the attachments to your testimony, you reference the terms "predictive" and "protective" genetic information. What is the significance of the term "predictive," and is the term "predictive genetic information" the most scientifically accurate definition we can use in legislating against discrimination?

Mr. Coxson. Yes, I believe it is. At least it is the best-understood term in the scientific community. People understand what you are talking about when you say "predictive genetic information." When you say "protective genetic information," it is a catchall. What is protective genetic information? It is an open-ended term in a sense, and therefore we are concerned about its use in pending legislation.

Mr. Fletcher. Okay. Mr. Avary, I was looking through some information that we have on this case, and it does seem that they were looking for something that probably would have no likelihood of occurring. I think somebody sold them a test, and they didn't know exactly what they were doing.

So let me ask you, was there any time that you were made aware of the fact that you may have some genetic disorder that you might need to know about that would help you in the future or anything?

Mr. Avary. No. Part of the paperwork, including when they sent that to us, related to finding anything else wrong after extensive laboratory X-ray nerve conduction testing was done and the private physician would be given the results. So in other words, in return, I think they were going to find out if I was carrying the gene potential for colon cancer, and they would be nice enough to let my physician know that I might acquire that disease.

Mr. Fletcher. Do you know if they were going to do comprehensive genetic testing? It would absolutely cost a tremendous amount. It looks like they were going to test for some hereditary neuropathy, which may manifest as carpal tunnel syndrome usually at a much earlier age. Not that we are going to question how old you.

Mr. Avary. I think anytime you take seven vials of blood, when that diagnostic lab in Massachusetts said they only needed two vials, I just don't understand it. We just haven't come to a clear-cut reason why so many vials of blood were needed. We had people go in and they gave five vials of blood, and they called them back in because they needed to get to that number seven. So instead of taking two, they took five more from one gentleman and they ended up with ten.

Now, these guys are scared. I mean this one guy was prepping for his carpal tunnel surgery and they needed to check his blood in case he was a bleeder. So as soon as they came with the needle to take his blood, he ran out of the hospital. He had to come back in the next day for the surgery.

Mr. Fletcher. Let me ask you a question. You went through the EEOC procedures. Did that process provide you with protection from what the employer was doing? Were you protected against possible discrimination if they had uncovered something genetic that would have demonstrated a propensity towards the disease?

Mr. Avary. I have to praise the EEOC for what they have done. It was just a broad gamut of trouble.

Mr. Fletcher. My time is up. But if there were some changes to be under the EEOC that had to do with genetic discrimination how would we define it? What do you think would help cover the workers under this circumstance?

Mr. Avary. The language could say no genetic testing, unless it was with the consent of the person.

Mr. Fletcher. Thank you.

Mr. Avary. Thank you.

Chairman Johnson. Mr. Kildee.

Mr. Kildee. Thank you, Mr. Chairman.

Mr. Calvo, I spent 12 years in the Michigan legislature and was involved in your organization at that time. Many of our businesses are interstate or international in nature. We do have control over interstate commerce under Article I, Section 8 of the Constitution.

Wouldn't it be better to have a uniform Federal law, if that much of our business is interstate, than 50 States with different laws, particularly now? When the economy becomes tight, very often employees are transferred from one part of a company to another. Would it not be better to have a uniform law to address this issue?

Mr. Calvo. As I mentioned in my opening remarks NCSL does not have an official position, so I have to decline to answer the question. We have mechanisms in place to take positions on Federal matters, and we have not done so in this instance.

Mr. Kildee. When you do, would you let us know?

Mr. Calvo. I am sure we will.

Mr. Kildee. That might be very helpful to us. You might bring it up in the next meeting. I used to go to those meetings.

Mr. Coxson. Mr. Kildee, may I interject a point, because I am also a member of the National Conference of State Legislatures' blue ribbon panel on human genetic technology, and I followed the Michigan law that was developed. In fact when I testified last year in the Senate, I held up the Michigan law, at least the process, as a model process.

As you know, when the Michigan law was passed, it was passed unanimously, strictly bipartisan. That is what we hope to achieve here today. Speaking for our Coalition in the business community, we hope to be able to achieve a bipartisan dialogue in this area.

Mr. Kildee. That is good. I do think that happens in Michigan from time to time. Not regularly. We didn't do that in redistricting.

You mentioned, Mr. Coxson that if we carried over the language of Title 7 of the EEOC to ADA that that might address the problem. Does that indicate that what Ms. Slaughter is seeking to achieve is something good to achieve?

Mr. Coxson. Mr. Kildee, don't misunderstand me. I did not suggest that Title 7 should be amended. What I suggested was that perhaps the Americans with Disabilities Act

should be amended.

Mr. Kildee. I suggest that perhaps the concept of Title 7 could be carried over from EEOC and the language used to amend the ADA.

Mr. Coxson. I must make one point on that.

Mr. Andrews, I perhaps exceeded my authority a moment ago when I committed the Coalition or bound the Coalition to support an ADA amendment. I suspect they would, but I don't have the authority to commit them at this point.

With respect to Mrs. Slaughter, I want to commend Mrs. Slaughter, Mrs. Morella and others, who worked tirelessly on this issue in a number of sessions of Congress. They are to be commended for that. We think in principle she is right. We have perhaps problems with the wording and some of the provisions of her bill, such as unlimited punitive and compensatory damages, and direct access to court without exhaustion of remedies before the EEOC, and with some of the definitions that we think may result in unintended consequences.

And if I may, briefly, we feel under an interpretation of her bill that such normative behavior as visiting the sick and consoling the bereaved, which our traditions and social mores and laws should encourage, may in fact give the employer illicit knowledge that could then become the subject of litigation. We think that is wrong, and that she believes that is wrong too. We may be able to work on that, but that is the problem with broad definitions.

Mr. Kildee. No law, let alone legislation offered here, is offered on Mount Sinai. This is Capitol Hill.

Let me ask Mr. Avary a question, and I do appreciate your testimony. Not everyone in America is guided, protected, or has the resources of a labor union behind him or her. Has it been helpful in your case to have a labor union that could give you some guidance and direction and protection?

Mr. Avary. Yes, it has. It really has. You have another contact, another person to call, to lean on, who can guide you with a purpose like we are here today. If it weren't for the Brotherhood of Maintenance of Way, a private individual out there without the union, would have nobody to turn to. You would have to have people listen to you individually. I would say having the union is a luxury.

Mr. Kildee. Thank you very much. Thank you, Mr. Chairman.

Chairman Johnson. Thank you. Ms. Rivers.

Ms. Rivers. Thank you, Mr. Chair. I apologize to the panel for not being here earlier. I was coming from another event.

I have a number of questions, because in my other role in Congress on the Science Committee, I have had an opportunity to do a lot of research on this issue. As someone said earlier technology may not be as advanced as people think it is.

I think however, it is in fact much more advanced than people understand. And the question of whether or not six or seven vials of blood are taken really pales in face of the fact that as of each of you walk away from the table today, there is probably enough DNA on each of the cups that you have lifted to your lips, to perform the kind of diagnostic tests that we are talking about here.

So there are ways to do these kinds of tests without an employee having any idea that they are being done. It is no longer an issue of simply having blood taken. It can be a tissue thrown aside in the workplace, a half-eaten sandwich put away in the trash, it can be a glass that someone has sipped from.

I am very concerned particularly since there was an announcement made a couple of months ago that the largest security company in the country has just purchased the largest DNA laboratory. This was done because there is recognition, that employers' interest in having information on their employees is so great that it is seen as a growth industry. So I hope as we think about this issue, we do it with a very clear understanding of where we are headed in terms of the usefulness of the information.

Mr. Coxson, you said that you believed that limitations on the use of this technology by employers could keep employees from doing things that could have a salutary effect on them. Where would you see that happening? Where would it not be wise to have a voluntary agreement for the flow of information? Give me an example in which voluntary wouldn't be enough.

Mr. Coxson. Again, it relates to specific definitions in the existing legislation, which cause us concern. Whether or not such things as employer-provided wellness programs, which I would consider salutary, would in fact be prohibited or impaired or impeded as a result of legislation, the reason being the genetic information received through those types of programs, family medical histories, and things like that. These could be imputed to the employer for purposes of litigation.

Ms. Rivers. That is why I said voluntary.

Mr. Coxson. I think I would have to say that if we are talking about voluntary consent of an employee to release or reveal genetic information, we would be supportive of that. We think it should be with informed consent.

Ms. Rivers. There are wellness programs in existence now and most employers, I have to assume the vast majority of employers, do not collect DNA or genetic information from those wellness programs. If they choose not to, do you read the law as saying the employers could not offer wellness programs if they don't collect that kind of information?

Mr. Coxson. Well, the question is not whether they test, because some perhaps do and some don't, but most wellness programs have as baseline information relating to family.

Ms. Rivers. This is information that the individual gives, right?

Mr. Coxson. Included under the proposed legislation is the definition of predictive genetic information or protective genetic information, which could trigger the type of potential liability and certainly litigation that I think we want to avoid.

Ms. Rivers. So if the employee goes into the company gym and sits down with the fitness expert, and the fitness expert asks if there is any heart disease in the family, or any diabetes, you would see that as triggering some sort of liability for the employer under the law?

Mr. Coxson. Under the legislation.

Ms. Rivers. Under the proposed law.

Mr. Coxson. In fact, you hit on a very good point that illustrates the type of water-cooler conversations on the job or off the job, in which an employee reveals that there is a problem in his or her family with respect to a particular illness. If that conversation is imputed to the employer and gives the employer this, "illicit knowledge", yes, I think that it could potentially trigger litigation and liability.

Ms. Rivers. This could happen of course, if and only if the employer then does something that appears to be discriminatory after receiving the information.

Mr. Coxson. That is exactly right. However, speaking as a management-side lawyer who has represented employers before juries in employment discrimination matters, it is very, very difficult. Once you get to a jury and you have an individual such as Mr. Avary and his lawyer sitting on the other side with obviously a very sympathetic story and one that everyone is sympathetic to, it is very difficult. Even if a decision had been made that was based on performance and not based on genetic information, it is very hard to convince the jury. Employers don't want to take that risk. So they will settle out of court at all cost in order to avoid the runaway jury awards.

Ms. Rivers. Then why do employers try to get this genetic information? Why does this company feel it is such a growth market out there that they will purchase a lab? If you are saying that the decisions are performance based, why get genetic information, ever?

Mr. Coxson. First of all, I am not convinced or I don't know whether the reason they purchased it is for use in employment decisions. It could be because the scientific research involved is expanding and therefore it is a good investment for that reason. I can't explain.

In the surveys carried out by the AMA and SHRM, employers don't generally require this information. I can't explain the circumstances under which it is required. For example, in the situation of Burlington Northern, I can't explain it.

But there are exceptions, even in the pending legislation, with respect to safety and health monitoring under Federal and State laws and things such as that. So there are instances where employers not only would want this information for nondiscriminatory purposes, but also are required by law to monitor or collect this information under OSHA.

Ms. Rivers. Collect genetic information?

Mr. Coxson. Well, for example, exposure to particular substances in the workplace that are regulated by OSHA. Some of these standards require employer monitoring.

Ms. Rivers. For damage?

Mr. Greenberg. Ms. Rivers, when we did our follow-up phone calls and interviews to human resources managers whose companies indicated in our questionnaire that they did genetic testing, we found a manufacturing company that used chemical coatings that had changed to a different kind of chemical coating. The company had some concerns as to whether or not there would be a reaction among workers dealing with this stuff.

They went to OSHA and voiced these concerns, and it was OSHA who recommended that this company do genetic testing on their employees.

Ms. Rivers. Genetic testing for predisposition to a particular metal?

Mr. Greenberg. To a particular set of chemicals, as I understood it. So there are, arguably, instances where this kind of information is taken with an eye solely towards the health and safety of the employee.

Ms. Rivers. Thank you.

Chairman Johnson. Your time has expired Ms. Rivers.

Mr. Payne.

Mr. Payne. Thank you very much. As you know, I missed most of the testimony and was quickly looking over a memo regarding this.

I am a cosponsor of H.R. 602, legislation introduced by Mrs. Slaughter and Mrs. Morella to prohibit genetic discrimination with respect to employee health insurance under Title 1.

I do think we are getting into a dangerous area. I wonder how we were able to make it all these years as a Nation that has exceeded other countries in the world? We came into World War II without having ships and planes, and within a year we had the greatest fleets and the best flying planes. We had men and women working to defeat the Axis to prevent Europe from being overrun. I don't remember these kinds of genetic tests and X-rays and fingerprints during that time.

First of all, I just think that it is a way to discriminate. In my opinion because the workplace is going to shrink, as we know it, a certain number of people simply are not going to be necessary. Just as we throw away diapers and cans and bottles today, we throw away society; so we throw away people.

We want to make sure we are perfectly right. As a matter of fact, we are talking about genetically altering foods, and I guess the next thing will be people, too. So I think it is overdone. I think that it is an intrusion. I think it is wrong. I think it is immoral, actually, and I will stand strongly against discrimination based on anything.

I think that employers should hire a person, or not, based on whether they can do the job; and then the person should take the physical. I think the physical should not be a discriminating part of employment.

Now, let me ask a question of the insurance people. If a person has had a mastectomy, does a company have a right to discriminate against hiring that person Mr. Coxson?

Mr. Coxson. Actually, we don't represent the insurance industry, so I can't speak from the insurance perspective. But I believe that would be prohibited currently under the Americans with Disabilities Act.

Mr. Payne. Someone was mentioning that OSHA feels it is necessary to do some of these tests. Was that you, Mr. Greenberg?

Mr. Greenberg. Not for a minute would I suggest that this is a widespread practice at OSHA. This is a single instance that our researchers became familiar with when these calls were made in 1998. A company described its experience to us with a change of a chemical nature of the coating that they used in their manufacturing process, and were concerned about the effect that this new mixture might have on their employees. One action that OSHA recommended to address these concerns was to perform genetic testing to see whether or not there was some kind of propensity towards a bad reaction to these particular chemical mixtures. So not for a minute am I suggesting this is a widespread practice. This is an instance that we found out about in our research.

Mr. Coxson. Mr. Payne, you raise a broader and a more profound point, I think, than OSHA. And that is, the very genetic information that is being censored today in this type of legislation, may very likely be information that a few years from now must be shared to help someone delay the onset of a disease or to avoid it entirely.

The science is evolving so quickly that I think if we act precipitously in legislation, we may find ourselves saying no, no, no in a few areas in which we don't want to prohibit disclosure of that information. We think you must disclose it because it is in an individual's interest to know, and the employer's interest at that time to know, what types of conditions will accelerate the onset of disease. I think we need to be careful for that reason.

Mr. Calvo. Mr. Payne, you also mentioned one additional point I think is very important. You mention the post-offer physicals that are somewhat common in

employment practice. I think it is important that the ADA does permit under certain circumstances, with conditions in place, unlimited medical testing and inquiries after you offer a job but before that person takes their job. So the ADA, in this one instance, doesn't allow employers to conduct genetic tests without any significant restrictions. They cannot, according to the ADA, discriminate on the basis of that information; but they can conduct those tests, and that is an issue that many States have grappled with.

Mr. Payne. My time has probably expired, but I think you mentioned, Mr. Coxson, that in the future it might even get worse. I think if there was a certain amount of security, or people felt confident in the employer, then there wouldn't be this question of will I be discriminated against or not.

But in this age of health care concerns about the cost of it, the lack of it, the HMOs trying to keep from paying bills, pushing people out of hospitals and "drive-by" hospital stays, do we have to pass a Federal law to allow a person to stay in the hospital up to 48 hours when they have delivered a child, and not be rolled out in 24 hours with bottles and tubes attached to them? There is no reluctance on the part of the average person to feel that the employer isn't necessarily looking out for the employee but that the employer of course is concerned about liability and the cost of insurance.

I think that is where the skepticism comes in, and I think it is just past practices, past behavior, and the history of employment exploitation through the years that gives some of us gray-haired men and women a little trepidation at a new surge of discriminatory practice.

Thank you for the your generosity with the time, Mr. Chair.

Chairman Johnson. Thank you, Mr. Payne. I have just a couple of comments.

Mr. Avary, we appreciate you being here. I understand the situation that you were put under. I am glad that the government rules that are in place helped you. I think that in the future we are going to have to look at this issue very closely.

Mr. Coxson, answer just one more question, if you would. What is a reasonable expense incurred to defend a case of this nature, even if it is won, for the employer?

Mr. Coxson. If it is an individual case, I think you are talking about, in legal defense fees, probably $20,000 or more if it goes into Federal court litigation. I think that despite the legal costs, because of the potential exposure to liability, you will find many employers, even if they believe that the charge is frivolous and not meritorious, will settle out of court for $25, 000 to $50,000.

Chairman Johnson. What kind of impact would that have on a small business, or even an employee himself?

Mr. Coxson. It is disruptive for any business, but for a small business it could be ruinous. But then so could a runaway jury award.

Chairman Johnson. Bankrupt?

Mr. Coxson. It could potentially bankrupt a small employer. Getting back to the point about conversations and inadvertent ways of discovering this information, Mr. Chairman, it is not uncommon for employees to share family problems with co-workers, supervisors, and business owners, or even to seek their assistance in times of trouble, especially in small business workplaces. And that is the type of thing that could be impeded, because the employer doesn't want to possess this information.

We tell our clients, you don't want this information because you can't do anything with it. It is too remote, and too speculative to make any present employment decisions with and can only get you in trouble. That is what we counsel our clients.

Chairman Johnson. Thank you. Mr. Andrews?

Mr. Andrews. Thank you, Mr. Chairman.

Mr. Greenberg, to the extent of your confidentiality obligations to those whom you survey, we would be interested in hearing more about this one episode in which OSHA counseled the use of genetic testing.

Mr. Greenberg. We will go back to the notes that our interviewers made in 1998 and supply you with everything we have, so long as we can be assured of confidentiality.

Mr. Andrews. Sure. I appreciate that.

If I may also echo something Mr. Kildee said about the importance of a uniform standard. It is my understanding that in Mr. Avary's case, his test results would have been sent to a lab in Massachusetts for analysis, and Massachusetts has a statute that requires consent by the person being tested. But there wasn't any effort by the Massachusetts lab to ask for consent, because Mr. Avary is not a citizen of Massachusetts. It is a query whether or not they are required to do that, because he is not a citizen of Massachusetts. So I think it is important to have a uniform national standard in this regard.

Mr. Chairman, I yield back.

Chairman Johnson. Thank you, sir.

I want to thank the witnesses for their valuable time and testimony and all Members for their participation. There being no further business, this Subcommittee stands adjourned.

Whereupon, at 3:34 p.m., the Subcommittee was adjourned.

APPENDIX A - WRITTEN OPENING STATEMENT OF CHAIRMAN SAM JOHNSON, SUBCOMMITTEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE

OPENING STATEMENT OF REP. SAM JOHNSON (R-TX),
CHAIRMAN

SUBCOMMITTEE ON EMPLOYER-EMPLOYEE RELATIONS

GENETIC NON-DISCRIMINATION: IMPLICATIONS FOR EMPLOYERS AND EMPLOYEES

TUESDAY, JULY 24, 2001

2175 RAYBURN HOUSE OFFICE BUILDING

GOOD AFTERNOON. LET ME EXTEND A WARM WELCOME TO ALL OF YOU, TO THE RANKING MEMBER, MR. ANDREWS, AND TO MY OTHER COLLEAGUES. TODAY'S HEARING FOCUSES ON GENETIC NON-DISCRIMINATION AND IT'S IMPLICATIONS FOR EMPLOYERS AND EMPLOYEES. AS YOU ALL KNOW, GENETIC NON-DISCRIMINATION IS AN ISSUE BECAUSE OF THE POTENTIAL FOR PRIVATE GENETIC INFORMATION TO BE USED IN INAPPROPRIATE CIRCUMSTANCES. OFTEN CITED EXAMPLES INCLUDE THOSE IN WHICH KNOWLEDGE OF A SPECIFIC DISEASE, CANCER FOR EXAMPLE, IN AN INDIVIDUAL'S FAMILY HISTORY WOULD BE USED TO DISCRIMINATE AGAINST THE INDIVIDUAL IN HIRING PRACTICES. WITH THAT SAID, LET ME MAKE IT CLEAR THAT THE MEMBERS OF THIS SUBCOMMITTEE ARE STRONGLY OPPOSED TO GENETIC DISCRIMINATION. EMPLOYMENT DECISIONS SHOULD ALWAYS BE BASED ON A POTENTIAL EMPLOYEE'S QUALIFICATIONS AND ABILITY TO DO THE JOB WELL, NOT ON FACTORS – GENETIC OR OTHERWISE – THAT HAVE NO BEARING ON JOB PERFORMANCE.

LAST YEAR RESEARCHERS AT THE NATIONAL INSTITUTES OF HEALTH (NIH) ANNOUNCED THAT THEY HAD SUCCESSFULLY COMPLETED A "ROUGH MAP" OF THE HUMAN GENOME. THIS MADE POSSIBLE A WHOLE NEW UNIVERSE OF SCIENTIFIC DISCOVERY – ONE THAT WILL CONTRIBUTE TO THE PREVENTION AND CURE OF HUMAN DISEASE. THE ANNOUNCEMENT ALSO SPURRED A PUBLIC POLICY DEBATE ABOUT GENETIC INFORMATION AND WHAT SPECIFIC PROTECTIONS SHOULD BE ACCORDED TO THIS NEW UNIVERSE OF INFORMATION.

SEVERAL EXISTING FEDERAL LAWS GOVERN THE PRIVACY AND USE OF GENETIC INFORMATION, AND THE PROTECTION OF DISCRIMINATION BECAUSE OF GENETIC FACTORS. IN ADDITION, MORE THAN HALF OF THE STATES HAVE ENACTED LAWS THAT FURTHER RESTRICT THE USE OF GENETIC INFORMATION IN HEALTH INSURANCE UNDERWRITING AND EMPLOYMENT DECISIONS.

THIS SUBCOMMITTEE HAS JURISDICTION OVER BOTH THE EMPLOYER-PROVIDED HEALTH INSURANCE AND EMPLOYMENT ASPECTS OF THE GENETIC

NON-DISCRIMINATION ISSUE. THIS IS OUR FIRST HEARING ON THE ISSUE – INTENDED TO LOOK AT CURRENT EMPLOYMENT LAW, STATE LAWS THAT IMPACT THIS ISSUE, CURRENT EMPLOYMENT PRACTICE, AND IMPLICATIONS OF THE ISSUE FOR BOTH EMPLOYERS AND EMPLOYEES.

TODAY, WE HOPE TO ANSWER MANY QUESTIONS ON THIS ISSUE INCLUDING 1) THE EXTENT TO WHICH CURRENT AMERICANS WITH DISABILITIES ACT AND STATE LAW ALREADY PROTECT INDIVIDUALS WITH GENETIC PREDISPOSITIONS TOWARDS ILLNESSES FROM EMPLOYMENT DISCRIMINATION; 2) THE EXTENT TO WHICH GENETIC TESTING IS PRACTICED BY EMPLOYERS; 3) LEGITIMATE USES OF GENETIC SCREENING AND MONITORING IN THE WORKPLACE TO PREVENT DAMAGE FROM EXPOSURE TO WORKPLACE HAZARDS; 4) ENFORCEMENT MECHANISMS AND PENALTIES, INCLUDING ADDITIONAL LIABILITY, WHICH ARE MOST APPLICABLE TO THIS SITUATION; AND 5) THE UNINTENDED CONSEQUENCES OF OVERLY BROAD DEFINITIONS OF GENETIC INFORMATION AND TESTING.

WE EXPECT TO FOLLOW THIS HEARING WITH OTHERS TO ADDRESS THE HEALTH INSURANCE AND FEDERAL LEGISLATIVE ASPECTS OF GENETIC DISCRIMINATION. I LOOK FORWARD TO WORKING WITH MY COLLEAGUES ON THE SUBCOMMITTEE TO ADDRESS THESE ISSUES. RIGHT NOW, I'D LIKE TO AKNOWLEDGE MY COLLEAUGE, MR. ANDREWS FOR HIS OPENING STATEMENT, THEN I WILL WELCOME ALL OF OUR WITNESSES. WE LOOK FORWARD TO YOUR TESTIMONY AND WHAT GUIDANCE IT WILL OFFER US AS WE ADDRESS GENETIC NON-DISCRIMINATION.

APPENDIX B - WRITTEN STATEMENT OF CHEYE CALVO, SENIOR POLICY SPECIALIST FOR THE EMPLOYMENT AND INSURANCE PROGRAM, NATIONAL CONFERENCE OF STATE LEGISLATURES, DENVER, CO

NATIONAL CONFERENCE *of* STATE LEGISLATURES

The Forum for America's Ideas

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California
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Executive Director

Genetic Non-Discrimination: Implications for Employers and Employees

Subcommittee on Employer-Employee Relations
Committee on Education and the Workforce
U.S. House of Representatives

Tuesday, July 24, 2001

Mr. Cheye Calvo
National Conference of State Legislatures
1560 Broadway
Suite 700
Denver, CO 80202

Washington
444 North Capitol Street, NW, Suite 515
Washington, D.C. 20001
Phone 202.624.5400 Fax 202.737.1069

Denver
1560 Broadway, Suite 700
Denver, Colorado 80202
Phone 303.830.2200 Fax 303.863.8003

Website www.ncsl.org

Chairman Johnson and members of the Subcommittee, I am Cheye Calvo, an employment and insurance policy specialist with the National Conference of State Legislatures (NCSL). NCSL is the national bipartisan organization representing the nation's 7,424 state legislators and their staff from all 50 states, the commonwealths and the territories. NCSL does not take positions on matters internal to the states and has not taken an official position on federal proposals to address genetic information in the workplace. I am here today to share with you the lessons of the states and frame the policy issues for regulating genetic information in the workplace based on a decade of state experience.

Human genetic technologies may prove the defining scientific advancement of the twenty-first century. The genomic science that promises to revolutionize medicine and enhance public health also presents threats to civil liberties and personal privacy. State lawmakers have come to recognize the challenges of crafting public policy for a technology that is only beginning to take shape.

State lawmakers understand that the role of law for human genetics is to guide the technologies—not to control them. In turn, they have enacted genetics protections as preventive measures to guard against misuse before it becomes widespread, and promote the use of these technologies to extend, enhance and save lives. State lawmakers also have come to appreciate the difficulties of framing law for rapidly emerging science. Several states already have updated laws enacted years before and many lawmakers foresee the need to regularly review state genetics policies to account for new developments and guard against unforeseen consequences.

This said, laws in 28 states—including six enacted this year—address the use of genetic information in the workplace. Forty-eight states also have state disability protections that—like the Americans with Disabilities Act (ADA)—may apply. All of these laws center around two related, but distinct issues: first, employers' use of genetic information; and, second, genetic testing and inquiries in the workplace. Key policy considerations include:

- Approaches to genetics protections;
- The scope of these protections;
- General exceptions; and
- Enforcement provisions.

The central policy issue is whether genetic information is special and requires higher legal protections or whether it is simply another form of health information and should be treated the same. The answer to this question largely influences the policy approach. The ADA allows employers to condition job offers on the completion of medical exams and conduct medical examinations and inquires on current employees that are "job-related and of business necessity." Therefore, an inclusive approach to genetics employment policy, based on the ADA, permits some degree of genetic testing. Genetic-specific laws place greater restrictions on employers' use of genetic information, and may include strict prohibitions on the use of genetic testing by employers.

Twenty-six states have taken the "exceptional" approach to genetic protections. Such laws may include adding genetic information to the list of other unlawful employment criteria—such as race and sex—or establishing entirely new bodies of law.

An inclusive approach may incorporate standards for the use of genetic information—either implicitly or explicitly—into current workplace disability protections, as has been done in Michigan and Illinois. Many also advocate that policymakers bolster disability protections or establish broader measures based on future or current health status. California and Minnesota, to some degree, have moved in this direction.

The second principal consideration relates to the scope of genetic protections. Scientists fail to recognize an absolute delineation between genetic and other health information. Therefore, laws must clearly define the realm of protections. All state genetics laws protect the results of predictive genetic tests, but many extend to other elements, such as information about genetic testing or services, the test results of family members, family history, and even inherited characteristics. Nine state laws exclusively cover predictive genetic information while others extend to diagnostic tests or genetic testing of any kind.

Regarding general exceptions, most state laws establish instances where genetic protections do not apply. The most common relate to employees that—due to a medical condition—are unable to perform essential job functions. Others allow exclusions if related to health or safety, to determine an employee's susceptibility to toxic exposures, or to investigate a workers' compensation claim.

Finally, most states enforce genetic employment laws through the same mechanisms that they assign for other unlawful employment practices. The primary method of enforcement is through private rights of action, following an administrative review and fact finding by the state agency or the EEOC. Several states, however, provide for specific civil liabilities, administrative fines, and criminal penalties for violators of genetic protections.

In conclusion, state lawmakers have been proactive in shaping an initial layer of public policy to govern genetic information in the workplace. Yet, they recognize that they will be called upon to revisit state genetics laws in the years ahead as the technologies continue to advance.

NCSL's Genetic Technologies Project was founded in 1995 to provide policymakers objective, accurate and comprehensive information and analysis to facilitate the drafting of sound genetics policy. NCSL has joined with Georgetown University Law Center and Johns Hopkins School of Public Health and Hygiene to conduct a three-year NIH-funded study of state genetics policy developments. NCSL maintains a legislative task force and blue ribbon panel of experts on human genetic technologies. The panel is current drafting four genetics policy reports on specific components of genetics policy, to be released in October 2001, including one on employment issues.

Additional information on genetics policy, state genetics laws and state legislative activity may be found online at http://www.ncsl.org/programs/health/genetics.htm.

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Cheye M. Calvo		
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).	Yes X	No
2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998: NIH Grant through Georgetown University Law Center, 'Genetics Legislation: Science, Syntax and Policy'		
3. Will you be representing an entity other than a government entity?	Yes	No X
4. Other than yourself, please list what entity or entities you will be representing: National Conference of State Legislatures NCSL is, under I.R.S. regulations, an instrumentality of the states.		
5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4: Senior Policy Specialist for NCSL's Genetic Technologies Project; do not represent a formal position taken by NCSL; testify to review state experience with genetics policy		
6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract: National Institutes of Health, $321,508.00		
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:	Yes	No X

Signature: _____ Date: _____

Please attach this sheet to your written testimony.

CHEYE CALVO
Senior Policy Specialist

NATIONAL CONFERENCE OF STATE LEGISLATURES
EMPLOYMENT AND INSURANCE PROGRAM
GENETIC TECHNOLOGIES PROJECT

Cheye Calvo is a Senior Policy Specialist with the National Conference of State Legislatures (NCSL). Mr. Calvo directs NCSL's Employment and Insurance Program, which includes NCSL's Genetic Technologies Project. Mr. Calvo specializes in a broad range of issues, including employment policy, insurance regulation, workers' compensation, unemployment insurance, genetics policy, and civil justice liability and reform.

Mr. Calvo serves as project director for NCSL's joint NIH-funded project with Georgetown University Law Center and Johns Hopkins University, *Genetics Legislation: Syntax, Science, and Policy* and staffs NCSL's legislative task force and blue ribbon panel on human genetic technologies. Mr. Calvo represents NCSL on the national advisory boards of a number of genetics policy efforts, including the NIH-funded project, *Communities of Color and Genetics Policy*, the March of Dimes' project, *Genetics Literary Project*, Partnership for Prevention's genetics and disease prevention initiative, and an Association of State and Territorial Health Official's genetics working group. Mr. Calvo is currently co-authoring a comprehensive report of state genetics policy and editing four issue-specific genetics policy reports—employment, insurance, privacy, and reproductive technologies—all to be released in October 2001.

Additional activities include conducting a recent study of auto insurance rate-making for the Connecticut General Assembly and serving as NCSL's representative to an American Association of Motor Vehicle Administrators' working group on financial responsibility laws.

Recent publications by Mr. Calvo include a book on auto insurance ratemaking, *Pricing Auto Insurance* (April 2001); articles for *State Legislatures Magazine*, "From Laboratories to Legislatures" (September 2001), "Parental Leave as Unemployment" (October 2000), and "Engineering Genetics Policy" (September 2000); and other NCSL articles, "Insurance Information Privacy" (January 2001), "NARAB and the Future of Insurance Regulation" (November 2000), "Protecting Genetic Information" (June 2000) and "The Problem of Uninsured Motorists" (January 2000).

Mr. Calvo came to NCSL in 1999 from local government in Maryland, where he served as chief of staff for Prince George's County Councilwoman Audrey E. Scott. While in county government, he developed expertise in a wide range of local and state matters, specializing in fiscal, personnel and economic development issues.

Mr. Calvo taught American history at the University of Wyoming while performing graduate work in History, specializing in state governments in the early national period. A native of College Park, Maryland, Mr. Calvo attended St. Mary's College of Maryland and the University of Wyoming, receiving a BA in History. He resides in Denver, Colorado.

NATIONAL CONFERENCE OF STATE LEGISLATURES
GENETIC TECHNOLOGIES PROJECT

STATE GENETIC EMPLOYMENT LAWS

Several states acted against employer use of genetic information in the 1970s and '80s to prohibit employer discrimination against applicants with the sickle cell trait. Wisconsin in 1992 became the first state to broadly prohibit genetic testing and discrimination in the workplace. With Arkansas, Louisiana, Maryland, Minnesota, Nebraska and South Dakota enacting measures in 2001, genetics employment laws are in place in 28 states. The scope and functions of these laws vary widely. All laws prohibit discrimination based on the results of predictive genetic tests; some extend the protections to all genetic tests, information about genetic testing or services, test result of family members, family history and even inherited characteristics. Most states also restrict employer access to genetic information, with some prohibiting employers from requesting, requiring and obtaining genetic information, or directly or indirectly performing or administering genetic tests.

On the federal level, the Equal Employment Opportunity Commission (EEOC) in 1995 interpreted "disability" in the Americans with Disabilities Act to include genetic predisposition to disease, but conflicting rulings raise questions whether the Supreme Court would accept the EEOC interpretation. President Clinton issued an executive order in February 2000 that banned genetic discrimination in the federal workplace.

State	Statute	Genetic Nondiscrimination Covers					Genetic discrimination prohibited in hiring, firing, and/or terms, conditions or privileges of employment	Prohibits Employer From				Specific Penalties for Genetic Discrimination in Employment
		Predictive Genetic Information Only	Genetic Test Results	Information About Genetic Testing	Family History	Inherited Characteristics		Requesting Genetic Information	Requiring Genetic Information	Performing Genetic Test	Obtaining Genetic Information	
Alabama	No provision											
Alaska	No provision											
Arizona	§41-1463		X				X					
Arkansas	SB766-2001		X			X	X	X	X		X	X
California	Govt. §12926, Govt. §12940	X	X		X	X	X			X		
Colorado	No provision											
Connecticut	§46a-60		X		X	X	X	X	X			
Delaware	§19-710 to 711	X	X			X	X					
D.C.	No provision											
Florida	No provision											
Georgia	No provision											
Hawaii	No provision											
Idaho	No provision											
Illinois	§410-513/25, 215-5/356v		X				X					
Indiana	No provision											
Iowa	§729.6		X				X	X	X	X		X
Kansas	§44-1002, §44-1009		X				X	X	X		X	
Kentucky	No provision											

State Genetics Employment Laws

State	Statute	Genetic Nondiscrimination Covers					Genetic discrimination prohibited in hiring, firing, and/or terms, conditions or privileges of employment	Prohibits Employer From				Specific Penalties for Genetic Discrimination in Employment
		Predictive Genetic Information Only	Genetic Test Results	Information About Genetic Testing	Family History	Inherited Characteristics		Requesting Genetic Information	Requiring Genetic Information	Performing Genetic Test	Obtaining Genetic Information	
Louisiana	SB651-2001	X	X	X	X		X	X	X	X		
Maine	§5-19301, §5-19302	X	X	X	X	X	X		X			
Maryland	HB18-2001		X		X	X	X	X	X			
Massachusetts	§151B		X	X	X	X	X	X	X	X	X	
Michigan	§37.1201, §37.1202		X		X	X	X		X	X	X	
Minnesota	SB1721-2001		X	X			X	X	X	X	X	X
Mississippi	No provision											
Missouri	§375.1300, §375.1306	X	X			X	X					X
Montana	No provision											
Nebraska	LB432-2001		X				X		X			
Nevada	§613.345		X				X	X	X	X		
New Hampshire	141-H:3		X				X	X	X	X		X
New Jersey	§10:5-5, §10:5-12	X	X	X	X	X	X					
New Mexico	No provision											
New York	Exec §292, Exec §296	X	X				X	X	X	X	X	
North Carolina	§95-28.1A		X	X	X	X	X					
North Dakota	No provision											
Ohio	No provision											
Oklahoma	§36-3614.2	X	X				X	X	X	X	X	X
Oregon	§659.036		X				X	X	X	X	X	
Pennsylvania	No provision											
Rhode Island	§28-6.7-1		X	X	X	X	X	X	X	X		X
South Carolina	No provision											
South Dakota	SB2-2001		X		X	X	X	X	X	X	X	X
Tennessee	No provision											
Texas	§21.402	X	X				X		X			
Utah	No provision											
Vermont	§18-9333		X	X		X	X		X	X		X
Virginia	No provision											
Washington	No provision											
West Virginia	No provision											
Wisconsin	§111.372		X	X			X	X	X	X		X
Wyoming	No provision											

Source: NCSL (July 2001)
This information may be found online at http://www.ncsl.org/programs/health/genetics/ndiscrim.htm.
For more information, please contact:

Cheye Calvo or Alissa Johnson
NCSL—Denver
303-830-2200
Cheye.Calvo@ncsl.org
Alissa.Johnson@ncsl.org

From Laboratories to Legislatures...

Legislating in the genomic age is harder than policymakers ever thought.

By Cheye Calvo

State lawmakers have been working for a decade to prevent misuse of genetics tests by health insurers and employers. Policymakers feared that businesses, trying to guard against rising health care costs, might screen out workers at higher risk of future illness. And that's what lawmakers in 28 states, beginning with Wisconsin in 1992, were trying to prevent. Forty-four states passed laws that restrict the use of genetic information by health insurers.

But the first possible misuse of genetic testing is, instead, something for which lawmakers were unprepared, even as they tried to envision all possibilities.

A recent court case involving an employer using genetic tests on employees to limit its liability for workplace injury has nothing to do with health insurance. The genetic tests were used to identify reasons for current injuries, not to predict debilitating and expensive future illnesses.

This case has recharged the genetics policy debate by reopening questions that policymakers thought they had answered and raising new ones, revealing that legislating for the genomic age isn't as easy as they thought.

For instance, how do genetics laws interact with federal and state disability protections? What are the differences—if any—between genetic tests and other medical exams in the workplace? Where does workers' compensation fit into the picture? And can-or should-genetic testing be used to promote worker safety? Most important of all: Should job-related genetic testing be permitted or is genetic testing by employers never appropriate?

The one thing we know is that there are no easy answers—and state legislatures will be laboratories of genetics policy for many years to come.

WORKING ON THE RAILROAD

Gary Avary works for the Burlington Northern Santa Fe Railroad-federally regulated, exempt from state workers' compensation laws, operating 33,500 miles of route with more than 40,000 employees in 28 states.

When Avary filed a carpal tunnel claim as work-related, the railroad ordered him to take blood tests. Curious, Gary's wife Janice, a nurse, asked what kind of tests. The response? Genetic tests.

Gary was one of 35 workers who turned in carpal-tunnel claims and were ordered to give blood samples. The railroad told employees only of laboratory testing to determine whether the injuries were work-related. Railroad doctors drew several vials of blood from workers, but never informed them of the genetic tests.

Only Avary learned in advance and refused. Burlington Northern threatened to fire him.

What the railroad wanted was to screen for a rare genetic disorder-hereditary neuropathy with liability to pressure palsy (HNPP)-for which carpal tunnel is a symptom.

Carpal tunnel is a disorder caused by pressure on the middle nerve at the wrist and linked to repetitive motion activities, such as typing or—in Avary's case—operating heavy machinery. Under a rule issued by President Clinton, such conditions were the burden of employers, and workers were guaranteed wage replacements for lost work. Hence, it would benefit the railroad to show it was genetic and not work-related.

But Congress overrode the regulation in February, so the debate over who is financially responsible persists.

In Avary's case, the Equal Employment Opportunity Commission (EEOC) filed a court action in February under the Americans with Disabilities Act (ADA) to force Burlington Northern to end testing. The ADA forbids medical testing of employees that is not job-related. The EEOC alleged the railroad was testing employees without their knowledge or consent. Also, the commission had ruled in 1995 that a genetic predisposition to a disease was a disability protected under the ADA.

"I like to come back to the underlying principle of the ADA that people should be treated based on their ability to do the job and not on some predictive genetic marker," explains EEOC Commissioner Paul Steven Miller.

Burlington Northern settled the case in April. It agreed to end the program and not punish employees who opposed the testing or participated in the EEOC proceedings—including Avary. The railroad has yet to resolve lawsuits by workers for millions of dollars in compensatory and punitive damages revolving around the mandated testing.

PREVENTING MISUSE

Workplace genetics laws narrowly focus on the use of genetic testing by employers. Of the states where Burlington Northern drew blood for genetic tests, some—such as Iowa, Kansas and Wisconsin—have laws governing genetic discrimination in the workplace; others—like Missouri, North Dakota and Washington—do not. Minnesota and Nebraska (where the Avarys live) enacted laws following

Cheye Calvo is NCSL's expert on employment and insurance issues.

the EEOC action.

But if disability laws already cover genetic testing, are genetic laws necessary? Perhaps.

The ADA applies in the Avary case because railroad workers are not covered by workers' compensation, but the act may not prevent genetic testing of injured employees that fall under workers' compensation laws.

The ADA allows medical exams to investigate workers' compensation claims. Consequently, genetic tests could be allowed in order to investigate claims.

The ADA also allows unrestricted medical examinations and inquiries between the time an employer makes a job offer and the employee starts work. The idea behind this is to allow the employer to look for any disabilities that may prevent the individual from performing the job. But allowing genetic tests before a worker starts a job also allows an employer to examine new workers for future health risks, and not just conditions that can harm job performance.

States are the ones addressing the gaps in the ADA. Laws in California and Minnesota go beyond the ADA to impose the "job-related" standard to medical examinations after an offer of employment is made. Twenty-two of the 28 genetic-specific employment laws prohibit testing by employers, in addition to genetic discrimination. But some—such as Iowa, New Hampshire and Wisconsin—include exceptions for investigating workers' compensation claims and to determine if an employee is at higher risk if exposed to toxic chemicals.

Many state genetic privacy laws also require consent before performing a genetic test. Burlington Northern sent employees' blood samples to Massachusetts to be analyzed by Athena Diagnostics. Yet, Athena failed to require written consent as required by the state.

"This is exactly the type of abuse that our genetic privacy and antidiscrimination law was designed to prevent," says Senate Majority Leader Linda J. Melconian, who sponsored the legislation enacted in August 2000.

"An individual's genetic makeup is the most personal and private information he or she possesses and should receive the highest level of protection under the law."

UNDER THE RADAR

With genetics policy debates focused on the potential for unfair discrimination in health insurance and employment decisions, workers' compensation has flown below the radar. Until now.

"Burlington Northern is a very different situation from what most states have been considering," says Senator Pam Brown, who sponsored genetics employment legislation enacted in Nebraska this year. "This case looks at an employer testing already injured workers in search of a genetic link."

Among the many questions it raises, the Burlington Northern case poses whether genetic testing has a role in workers' compensation. All states except Texas require employers to insure employees against workplace injuries. Workers' compensation is founded on the theory that employees cover medical costs and lost wages that result from work-related injuries in exchange for the employees giving up their right to sue.

The key qualification is "work-related." Burlington Northern's genetic testing program apparently tried to make the case that a worker's predisposition for a particular disorder could disqualify it as a work-related injury and potentially limit its liability.

Genetic testing to investigate workers' compensation claims would aim to diagnose conditions already present rather than predicting possible future illness. As a result, protections that guard against predictive genetic testing may not apply.

The policy question may be whether state workers' compensation systems should hold employers fully responsible for workplace injuries that are genetic in nature. State workers' compensation laws generally hold employers responsible for injuries that are in any way work-related, but it is more difficult to pinpoint the source of soft tissue injuries, like carpal tunnel (which is increasingly common with today's workforce), than industrial accidents.

As scientists decipher the human genome to better understand the genetic, environmental and behavioral components underlying disease, tests may be invented to identify whether certain illnesses are work-related or caused by genetic factors.

"There has to be a level of protection for workers," says Maryland Delegate Tony Fulton who introduced legislation this year to prohibit the use of genetic testing to investigate a workers' compensation claim. "It is only fair and reasonable to prevent an invasion of privacy that may be used to deny people benefits or put them at a disadvantage when negotiating with management."

WORKER SAFETY

There is another side to the genetic testing issue raised by the Burlington Northern case. If an employer used genetic testing to identify individuals at higher risk of occupational illness and took steps to prevent it, that would be a step in the direction of greater workplace safety.

Paul Billings, co-founder of GeneSage and a key player in California's genetics legislation enacted in the 1990s, says genetic testing, if done correctly, offers an effective tool to prevent otherwise unavoidable exposure. "Employees have a natural interest in knowing what their biology brings to the workplace," he says.

For example, working around beryllium—a metallic element used in nuclear reactors and aerospace design—can cause chronic beryllium disease, which hardens the lungs and leads to death by suffocation. Although federal standards for beryllium dust on job sites limit workers' contact with the substance, some people are genetically prone to the disease with only the slightest exposure.

Billings points to the Los Alamos government labs in New Mexico, major beryllium users, which are considering a voluntary genetic testing program. The plan has the employer pay for the tests, but restricts test information to employees, who alone decide how to use that information.

Employers worry about how to permit the use of genetic testing for beneficial purposes, like worker safety, but not for discrimination. "Employers don't know where the technology is going, but want to leave the door open for scientific and medical advances," says Harold Coxson, a partner in the national labor and employment law firm of Ogletree Deakins. "The world could look much different in five years than it does today."

Others are pleased to prevent any direct use of genetic testing by employers. "As a policy matter, we should not encourage employers to screen out susceptible individuals rather than putting in place the appropriate environmental controls," said Vicki Laden, who heads the City of Oakland's employment law division and filed a brief in the Burlington Northern case.

Voluntary, confidential programs that warn workers of increased risks for rare conditions are one thing, but few employers are set up to put in place the appropriate protocols for genetic testing, like counseling, Laden says.

EEOC Commissioner Miller says that it is important to uphold the high standard of the ADA and require employers to demonstrate how any genetic testing is job-related. "Beryllium may be a good example of appropriate testing, but it may also be the only example."

Barbara Fuller with the National Human Genome Research Institute echoed this cautious outlook for the imminent application of genomic science in the workplace. Only a small number of diseases are linked to one gene, she says. Instead, most disorders are caused by a complex interaction among 10, 20 or 30 genetic mutations and environmental factors, making genetic testing to predict a person's risk of future disease very difficult.

"In the future, employers may come to better understand the risks they pose to the health of their employees, and employees may be better informed of workplace hazards. But genetics isn't everything," says Fuller. "Genes rarely predict a health outcome with 100 percent certainty, and employees should be allowed to weigh what risks they are willing to take."

WHAT WE DON'T KNOW

Genetic technologies appear to be advancing rapidly, but the impression is exaggerated by the fact that we know so little and understand less. For example, we're just beginning to know how many genes there are. The best scientists in the world—after billions of dollars in research—told us as recently as January that human beings possessed between 80,000 and 100,000 genes. In February, they revised the estimate to about 30,000 genes—about twice as many as a worm or fruit fly.

It was a humbling revelation, on so many levels, but underscores the reality that genetic exploration remains in its infancy. Policymakers have an even less firm foundation. They must craft genetics policy that protects against potential misuse of a technology that is just beginning to taking shape.

"It's not easy coming up with language that covers everything that will happen and does not have unintended consequences," said Senator Brown. "We are going to be tweaking genetics legislation on all levels on a regular basis as the technology burgeons. We can't pass a law and say we've dealt with it. This is ongoing policymaking."

APPENDIX C - WRITTEN STATEMENT OF GARY AVARY, EMPLOYE, BURLINGTON NORTHERN SANTA FE RAILROAD COMPANY, ALMA, NE

Testimony of

Gary Avary, Member

Brotherhood of Maintenance of Way Employes

and Employee, Burlington Northern Santa Fe Railroad Company

before the

Committee on Education & the Workforce

Subcommittee on Employer-Employee Relations

U. S. House of Representatives

"Genetic Non-Discrimination: Implications for Employers and Employees"

July 24, 2001

Good afternoon and thank you for inviting me to testify at this Subcommittee hearing.

My name is Gary Avary, and I'm from Alma, Nebraska, population 1,200. I'm 45 years old, and have been married for 28 years. Janice and I have three daughters and one grandson. I have worked for Burlington Northern Santa Fe railroad for 27 years in the track and maintenance department, and am a 27-year member of the Brotherhood of Maintenance of Way Employes (BMWE) union.

In September 2000 after working on several derailments over a short period of time I started having pain and numbness in my right hand specifically in the fingertips. This made it very difficult to do many aspects of my job safely since derailment repairs require many continuous hours of using high impact, vibrating tools.

On September 13, I saw a hand/shoulder/arm specialist and had extensive testing done. I was diagnosed with carpal tunnel syndrome or CTS. This is swelling and scarring of the tunnel in the wrist that carries the nerves to the hand. CTS is caused by extreme temperature changes and continuous repetitive activity.

About a week later, the railroad authorized surgery and on September 28, I had laparoscopic repair done. Three weeks later, I was back at work with 100% use of my hand.

On October 24, the railroad's medical department requested all of my medical records pertaining to my CTS exams and surgery to further evaluate workplace responsibility. During this time my medical insurance paid for the surgery and BNSF paid all expenses not covered by the insurance plan.

In December I received a registered letter from the company notifying me of a required mandatory medical exam which would include X-rays, nerve tests, and laboratory tests.

When my wife and I found out from a co-worker that as part of his test the lab took seven vials of blood, we started questioning. My wife, a Registered Nurse, started making phone calls to find out what these tests were and was told "accidentally" that a genetics test would be included.

She was told by several people – an appointment coordinator, a secretary, and the Chief Medical Officer at BNSF – that this exam was mandatory according to a corporate internal rule 26-3 regarding mandatory medical exams. By not going to this exam, I would be considered an insubordinate employee and fired.

My wife then contacted an FELA attorney who represents BMWE union members to see if this was legal. It was not. Then we contacted the EEOC for job protection for me. I am more fortunate than most people in the workforce because I have the union to support, protect, and guide me through this. I did not go to the company required doctor's appointment on January 5, 2001, so in turn the railroad notified me by registered letter that my behavior was under disciplinary investigation and set a date for a hearing on that matter. If you work for BNSF you know this means that you will be fired. After attempts by the union to cancel this investigation, the railroad changed the date but did not cancel the hearing until the EEOC and a Federal judge ordered them to do so. I still work for BNSF under protection of the EEOC whistle blowers act.

Since this began, my wife and I have been doing extensive research into the issue of genetic discrimination. We have talked to individuals from all over the U.S. who have lost their jobs and/or insurance coverage because of actual or potential diseases.

We are strong supporters of H.R. 602 and S. 318 introduced by Congresswoman Louise Slaughter and Senator Thomas Daschle respectively. They have been trying to get genetic

nondiscrimination protection passed for five years. This type of discrimination has been happening all along, but no one wanted to believe it. A law that protects all federal employees from this type of testing and discrimination was passed during the Clinton Administration.

I think it is time all Americans are protected from this type of mandatory testing and discrimination.

What happened to me should not happen to anyone especially in the United States. It is a direct infringement on our fundamental right to be who we are. No one can help how they are put together, only God knows that, and your employer, insurance companies or anyone else has no business of that knowledge. That information should be shared only if you voluntarily request the testing. Then it can be used to your benefit. It should not be used against you and your family for hiring and firing practices, or acceptance and/or denial into insurance programs.

Please help us get strict federal laws passed so that this type of testing and discrimination can't happen to anyone else in the future.

Thank you.

CMTE ON ED & WORKFORCE

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Gary L. Reay		
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).	Yes	No ✓
2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998:		
3. Will you be representing an entity other than a government entity?	Yes ✓	No
4. Other than yourself, please list what entity or entities you will be representing: BMWE		
5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4: Union		
6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract: None		
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:	Yes	No ✓

Signature: Gary L Reay Date: 7-24-01

Please attach this sheet to your written testimony.

CMTE ON ED & WORKFORCE

PERSONAL INFORMATION: Please provide the committee with a copy of your resume (or a curriculum vitae). If none is available, please answer the following questions:

a. Please list any employment, occupation, or work related experiences, and education or training which relate to your qualifications to testify on or knowledge of the subject matter of the hearing:

I have worked for Burlington Northern Santa Fe railroad for 27yrs

The discrimination suit promted me to do extensive research into the subject of Genetic testing and the ways it could be used against the people of the united states. (Employment, insurance)

b. Please provide any other information you wish to convey to the Committee which might aid the members of the Committee to understand better the context of your testimony:

Please attach to your written testimony.

APPENDIX D - WRITTEN STATEMENT OF ERIC GREENBERG, DIRECTOR OF MANGEMENT STUDIES, AMERICAN MANAGEMENT ASOCIATION, NEW YORK, NY

AMA American Management Association®

440 First Street, N.W.
Washington, DC 20001
202.347.3092 Phone
202.347.4549 Fax
www.amanet.org

Eric Rolfe Greenberg
Director of Management Studies

Congressional Testimony, July 24, 2001
Committee on Education and the Workforce
Subcommittee on Employer-Employee Relations

The American Management Association and its Board of Trustees appreciate this opportunity to share with the subcommittee the results of our research into workplace medical testing in general and genetic testing in particular. The AMA is not a trade association, and our charter prohibits us from lobbying for legislation. But as part of our core mission of management development and training, we perform surveys on a variety of management issues, establishing benchmarks and assisting the management community in policy development and implementation.

The AMA launched its first medically related survey in 1987, focusing entirely on workplace drug testing and drug abuse policies. Over the years, the annual survey questionnaire was expanded and revised to include other forms of workplace testing. The last major revision of our questionnaire took place in 1997, when for the first time we asked about genetic testing.

In brief, what we found that year, and in subsequent years, is that genetic testing is rare in corporate America, and that it is not well understood among the human resources managers who complete our annual questionnaire.

In that 1997 questionnaire revision, with the help of Dr. Rosemary Orthmann, then editor of ***Employment Testing Law and Policy Reporter,*** we created a list of ten different forms of workplace medical testing. That list included the standard "fitness for duty" exam, testing for illegal substances, for the AIDS virus, for pregnancy, for "susceptibility to workplace hazards," and for such inheritable diseases as sickle cell anemia and Huntington's disease.

All of these testing categories were listed in a matrix that asked if companies performed such testing on applicants and/or current employees, and whether test results were used in decisions to hire job applicants, assign or reassign employees, and retain or dismiss employees. Let me immediately report that in that year and every subsequent year, we have found a great deal of testing for illegal substances, somewhat lesser testing for "fitness for duty," and practically no testing for inheritable diseases. Moreover, even among the few companies that performed such testing, an even smaller number used test results in determining whether to hire applicants and/or assign or dismiss current employees.

Specifically, now, about genetic testing:

As I said, "genetic testing" was listed among ten forms of medical testing in our 1997 questionnaire. When the results came back from 906 AMA member and client organizations, 52 companies, or 5.6% of those surveyed, had checked the box that indicated that they performed genetic testing.

We had no particular reason to doubt this figure. The only previous survey of which we knew, performed in 1989 by the Office of Technology Assessment on a much smaller sample, also found about five percent performing genetic testing. But, because we had no baseline data from previous years, we did not make our finding public in 1997.

In 1998, using the same matrix, we found an almost identical share of respondents – 5.2%, or 56 companies out of that year's sample – indicating that they performed genetic testing. Again, there was no particular reason to doubt the finding, but we were and are aware that this is a particularly sensitive issue, and we wanted to be sure we were right before we publicly released the finding.

And so we put our researchers on the phone to every human resources manager we could contact who had indicated to us that their companies performed genetic testing. We reached 44 of them, and we found that 80 percent of them did **not** perform genetic testing in any way, shape, or form.

Under follow-up questioning, many HR managers told us they considered **any** blood test to be a "genetic test," and others thought that testing for the **presence** of a disease, as opposed to a genetic susceptibility, was a "genetic test." No more than nine companies – less than one percent of the 1,085 in that year's sample – did anything that might qualify as genetic testing.

One such company, a manufacturing concern, told us that they did indeed perform genetic testing on employees – and were doing so because they had been advise to do it by the Occupational Health and Safety Administration. Unanimously, the companies that did genetic tests told us they performed them for no other reason than concerns over worker safety and health.

The next year, in 1999, we took "genetic testing" out of the matrix with the other forms of testing. From Barbara Fuller of the Human Genome Project of the National Institutes of Health, we received a definition of genetic testing, and we printed it in a separate box in our questionnaire. The definition read:

> **The analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect heritable disease related genotypes, mutations, phenotypes, or karyotypes for clinical purposes. Such purposes include predicting risk of disease, identifying carriers, and establishing prenatal and clinical diagnosis or prognosis.**

Under this, our questionnaire asked, "according to this definition, do you perform genetic testing on job applicants? On current employees?"

In 1999, the first year in which we used this format, only three companies out of 1,054 checked "yes;" in 2000, seven companies out of a much larger sample of 2,133; and this year, two companies out of 1,627 surveyed.

If genetic testing is being done to any appreciable degree among AMA's membership and client base (who together employ one-fourth of the American workforce), we haven't been able to find it. It must be admitted, however, that if companies are using such testing for nefarious reasons, they would be unlikely to report it in an AMA survey.

Genetic testing is another tool that modern technology has placed in our hands, with the potential to be used for good or ill. It is easy to create nightmare scenarios in which people are judged not by their abilities but instead by their genetic propensities and susceptibilities. Indeed, Hollywood has already done that. But human resources managers in major US firms have to deal with reality, not fantasy, and insofar as AMA Research can tell, the reality is as stated: genetic testing is rare; where done it is performed with the health and safety of workers foremost in mind; and it is widely misunderstood.

For the record, I have furnished to the subcommittee a summary of findings from the AMA's 2001 survey on medical testing.

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name:		
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).	Yes	No XX
2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998: NONE		
3. Will you be representing an entity other than a government entity?	Yes XX	No
4. Other than yourself, please list what entity or entities you will be representing: American Management Association 1601 Broadway New York, NY 10019		
5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4: Witness is employed as Director of Management Studies for above not-for-profit membership association		
6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract: EPA Cooperative agreement for training & development, estimated amount at signing $2.6M, actual revenue $370K		
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:	Yes	No XX

Signature: _____ Date: 7/23/01

Please attach this sheet to your written testimony.

PERSONAL INFORMATION: Please provide the committee with a copy of your resume (or a curriculum vitae). If none is available, please answer the following questions:

a. Please list any employment, occupation, or work related experiences, and education or training which relate to your qualifications to testify on or knowledge of the subject matter of the hearing:

See attached

b. Please provide any other information you wish to convey to the Committee which might aid the members of the Committee to understand better the context of your testimony:

Please attach to your written testimony.

AMA American Management Association news

ERIC ROLFE GREENBERG

Eric Rolfe Greenberg currently serves as Director of Management Studies for the American Management Association. In this capacity, he has directed research and survey projects on such diverse topics as information technology, marketing, workplace testing and monitoring, and corporate restructuring. He has written numerous articles based on survey results, and appears frequently in print and on radio and television as an AMA spokesman on these and other subjects. He has presented AMA survey findings to a variety of forums, including testimony before various committees of the U.S. Congress.

Since joining the American Management Association in 1981, he has served with the groundbreaking Institute for Management Competency and with AMA's Development Department, helping in the reorganization of AMA's four-week Management Course. In 1984, he became Associate Editor, AMA Membership Publications, with responsibility for survey-based research reports. He is also a successful writer of fiction, whose acclaimed novel, The Celebrant, was recently re-issued by Bison Books.

1601 Broadway
New York, NY 10019-7420

212.903.8052 Phone
212.903.8404 Fax

egreenberg@amanet.org
www.amanet.org/research

AMA American Management Association
From AMA Research

news

2001 AMA Survey on Workplace Testing:
Medical Testing

Summary of Key Findings

Sixty-eight percent of major U.S. firms require medical examinations of new hires, current employees, or both. The figure compares with 70% found in AMA's 2000 survey and 74% in 1999; the decline from the 1999 finding is just outside the 2.5% margins of error for the respective years' samples and is therefore statistically significant. The decline has been driven by almost entirely by lesser testing of employees, while new hire testing has remained relatively constant.

	All Respondents				Business Category				
	1998	1999	2000	2001	Mfg	Financial Services	Whlsale & Retail	Business & Prof. Services	Other Services
All New Hires	48.7%	50.9%	51.7%	51.7%	69.3%	19.9%	40.1%	27.4%	37.4%
Selected New Hires	15.2%	17.4%	15.2%	13.6%	9.6%	7.7%	16.1%	15.4%	22.6%
Total – New Hires	63.9%	68.3%	66.9%	65.3%	78.9%	33.6%	56.2%	42.8%	60.0%
All Employees	5.2%	8.3%	6.3%	5.7%	7.1%	0.0%	3.3%	2.9%	5.9%
Selected Employees	38.0%	33.2%	30.3%	28.5%	31.2%	6.9%	27.6%	16.9%	34.6%
Total – Employees	43.2%	41.5%	36.6%	34.2%	38.3%	6.9%	30.9%	19.8%	39.5%
Total – Medical Testing	77.0%	74.0%	70.0%	68.4%	81.9%	31.5%	57.3%	47.4%	63.4%

In addition to those that require regularly scheduled examinations for employees, 45 percent of respondent firms require unscheduled exams when job performance suggests a medical problem. Also, 18 percent select employees at random to undergo examinations, generally as part of a workplace drug testing program. Drug testing is, in fact, the primary factor in workplace medical testing, practiced by 67% of major U.S. firms. "Fitness for duty" – establishing the ability of the applicant or employee to perform assigned job tasks – is by far the leading rationale for complete medical examinations, practiced by 50% of respondent firms. Testing in other categories is much less common.

				TEST RESULTS USED IN DECISIONS TO:			
TESTING CATEGORIES	Any Such Testing	New Hire Testing	Employee Testing	Hire Job Applicants	Assign or Reassign Employees	Retain or Dismiss Employees	Results Used in any Regard
Illegal Substances	66.7%	60.5%	50.1%	61.3%	11.9%	46.2%	68.1%
Fitness for Duty	49.6%	40.7%	32.9%	42.8%	24.6%	17.5%	50.9%
Susceptibility to Workplace Hazards	14.3%	11.9%	9.8%	8.7%	8.2%	2.8%	11.7%
Breast/Colon Cancer	2.9%	0.8%	2.7%	0.4%	0.6%	0.2%	1.0%
HIV Infection	2.2%	1.5%	1.3%	1.0%	0.7%	0.3%	1.7%
STDs	1.5%	1.4%	0.5%	1.2%	0.8%	2.5%	3.9%
Sickle Cell Anemia	1.3%	1.0%	0.8%	0.6%	0.4%	0.1%	1.0%
Pregnancy	0.8%	0.7%	0.2%	0.2%	1.1%	1.9%	3.2%
Huntington's Disease	0.4%	0.2%	0.4%	0.3%	0.5%	0.1%	0.8%
Family Medical Histories	20.1%	16.8%	9.7%	4.6%	1.4%	0.6%	5.5%

1601 Broadway
New York, NY 10019-7420

212.903.8052 Phone
212.903.8404 Fax

egreenberg@amanet.org
www.amanet.org/research

Comparisons with Previous Years: The AMA questionnaire has undergone several reconfigurations, adding new categories of inquiry in 1991, 1997, and 1999. Any alteration in questionnaire format may affect data findings, and year-to-year changes may be read in that light. Here, where applicable, are the decade-long time lines in major categories of medical testing:

	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Illegal or Controlled Substances:	73%	78%	76%	78%	81%	74%	74%	70%	66%	67%
HIV Antibodies:	9.5%*	4.4%	2.5%	0.7%	1.2%	5.2%	3.9%	2.8%	2.6%	2.2%
	*-includes voluntary testing									
Fitness for Duty:	NA	NA	NA	NA	NA	57%	58%	55%	48%	50%
Sexually Transmitted Diseases:	NA	NA	NA	NA	NA	4%	5%	3%	3%	2%

Genetic Testing: The HGP/NIH provided this definition of "genetic testing:"

> **The analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect heritable disease related genotypes, mutations, phenotypes, or karyotypes for clinical purposes. Such purposes include predicting risk of disease, identifying carriers, and establishing prenatal and clinical diagnosis or prognosis.**

Presented with this specific definition in our questionnaire, only **two** respondents answered that their firms performed genetic testing. While a much larger percentage (14.3%) that report testing for "susceptibility to workplace hazards;" not all such testing is "genetic" testing. Responding to our 1998 questionnaire, which asked ***with no definition presented*** if firms performed "genetic testing," 52 respondents (5.7% of the sample) said "Yes." But follow-up interviews with 44 of these human resources managers found that only nine of them had actual genetic testing programs. Some thought that any test requiring a blood sample constituted "genetic testing;" others thought that testing for the **presence** of a disease, rather than for a genetic **susceptibility** to that disease, was "genetic testing."

About This Survey

The annual AMA questionnaire on workplace testing and monitoring was mailed in January 2001to human resources managers in AMA member and client companies. By March 31, 1,627 usable responses were returned, forming the current database whose margin of error is 2.5%.

To give validity to year-to-year comparisons, the 2001 sample was weighted against the respondent bases for the previous three years. The sample accurately mirrors AMA's corporate membership and client base, who together employ one-fourth of the U.S. workforce, but because such companies are largely drawn from the top five percent of U.S. businesses in terms of annual sales and total employees, the sample does not accurately reflect policies in the U.S. economy as a whole, where smaller firms predominate.

Annual Sales	1999	2000	2001
Less than $10 million	6.8%	9.8%	9.7%
$10 million to $49 million	19.6%	18.5%	18.3%
$50 million to $249 million	30.4%	27.7%	27.6%
$250 million to $499 million	11.1%	11.9%	12.1%
$500 million to $999 million	7.9%	7.8%	7.8%
$1 billion or more	13.0%	13.2%	13.3%
Not reported	11.2%	11.0%	11.2%

Business Category	1999	2000	2001
Manufacturing	44.1%	50.3%	51.0%
General Services – for profit	24.3%	12.4%	9.5%
General Services – nonprofit	17.4%	10.9%	12.0%
Business & Professional Svcs	4.5%	8.3%	8.6%
Financial Services	2.4%	7.5%	7.7%
Wholesale & Retail	5.0%	8.5%	8.3%
Public Administration	1.2%	1.9%	2.5%
Not reported	1.1%	2.0%	0.3%

APPENDIX E - WRITTEN STATEMENT OF HAROLD P. COXSON, ESQ., PARTNER, OGLETREE, DEAKINS, NASH, SMOAK, AND STEWART, ON BEHALF OF GENETIC INFORMATION NONDISCRIMINATION IN EMPLOYMENT (GINE) COALITION

TESTIMONY OF

HAROLD P. COXSON, ESQ.

FOR THE

GENETIC INFORMATION NONDISCRIMINATION IN EMPLOYMENT (GINE)

COALITION

ON

"GENETIC NONDISCRIMINATION: IMPLICATIONS FOR EMPLOYERS AND

EMPLOYEES"

BEFORE THE

U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON EDUCATION AND THE WORKFORCE

SUBCOMMITTEE ON EMPLOYER-EMPLOYEE RELATIONS

JULY 24, 2001

Chairman Johnson and Members of the Subcommittee on Employer-Employee Relations. On behalf of the Genetic Information Nondiscrimination in Employment (GINE) Coalition, I wish to express our appreciation for the opportunity to testify before the Subcommittee on the subject of "Genetic Nondiscrimination: Implications for Employers and Employees."

My name is Hal Coxson. I am a Shareholder in the national labor and employment law firm of Ogletree, Deakins, Nash, Smoak & Stewart, P.C. and a Principal in the firm's government relations subsidiary Ogletree Governmental Affairs, Inc. I also serve as a member of the Employment Issues Committee of the National Conference of State Legislatures' Blue Ribbon Panel on Human Genetic Technologies. I appear before you this afternoon as Counsel to 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), the National Federation of Independent Business (NFIB) 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, and today's testimony before the Subcommittee is limited to that issue.

BACKGROUND

Members of the GINE Coalition, like the rest of society, are thrilled by and enthusiastically supportive of the scientific research and truly spectacular scientific breakthroughs relating to the sequencing of the human genome. We join the Nation in applauding the success of Dr. Francis Collins of the Human Genome Project, Dr. Craig Venter at Celera Genomics, and others responsible for these milestones in human civilization. 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. Collins recently predicted:

> "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 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 the hereditary basis for many of the profound diseases which bedevil us today will not only be identified, but such knowledge will 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.

Today's fear, however, is 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. Recent surveys of employers conducted by the American Management Association and the Society for Human Resource Management indicate that, in fact, employers do not require genetic tests nor use genetic information as the basis for employment decisions. There are equally compelling polls, however, which reveal that whether or not such fears are rationally based, employees fear that such information will be used by employers to discriminate and, therefore, those employees would be less likely to participate in genetic research. Such fears are supported most likely by anecdotal stories and, of course, on the rare but highly-publicized reported case, such as that recently involving Burlington Northern-Santa Fe Railroad. In fact, however, charges of employment discrimination based on genetic information have been extremely rare in the 28 states which have laws prohibiting such conduct and no reported cases, even though several statutes were enacted a decade ago. Similarly, only an isolated charge has been filed with the U.S. Equal Opportunity Commission (EEOC) under the Commission's 1995 interpretation of the Americans with Disabilities Act. Thus, there is little empirical evidence of widespread 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.

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, they 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 will become manifest. Thus, such information is simply too remote and, currently, too speculative on which to base present employment decisions.

Yet, it is the opinion of the sponsors and supporters of pending federal genetic nondiscrimination bills that such legislation is both "preventative" and necessary, whether or not there is evidence of actual, widespread employment discrimination.

THE GINE COALITION'S POSITION ON GENETIC NONDISCRIMINATION

The GINE Coalition has developed a set core of principles by which is measures genetic nondiscrimination legislation. (Attachment 1). In sum, the GINE Coalition's Statement of Principles embraces the letter and spirit of nondiscrimination; rejects notions of "genetic exceptionalism" from statutory remedies and procedures for other prohibited forms of employment discrimination; 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.

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. Employment discrimination based on genetic makeup is no more tolerable than other types of employment discrimination.

In that regard, there is no basis for legislative "genetic exceptionalism" which would single out genetic discrimination from all other forms of employment discrimination in terms of remedies, amount of damages, and administrative procedures available to aggrieved parties. Individuals alleging genetic discrimination should be entitled to no greater rights or protections than individuals alleging employment discrimination on the basis of race, sex, religion, national origin, or age. In particular, it makes no sense logically, legally, or equitably for asymptomatic individuals not currently, and hopefully never, disabled, to receive greater rights and be entitled to greater damages than those available to currently disabled individuals under the Americans with Disabilities Act ("ADA"). There is simply no reason why someone with a genetic marker who may never suffer a minute of disability should be entitled to greater protections than those protections afforded to a severely disabled individual.

Members of the GINE Coalition also believe that, as with other forms of employment discrimination, allegations of genetic discrimination should be required to be subject to the investigative, administrative enforcement, and mediation procedures of the U.S. Equal Employment Opportunity Commission prior to the filing of a lawsuit. Congress has established those mandatory procedures for other forms of employment discrimination, including disability

discrimination, as a method of investigating and resolving disputes. Such procedures should apply to allegations of genetic discrimination as well.

Further, being mindful of the rapid developments in genetic technologies and Dr. Collin's predictions regarding the beneficial use of genetic information in the near future, we believe that genetic nondiscrimination 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 discriminatory conduct, rather than attempting to regulate the flow of information. The law should not trigger liablility based on an employer's casual, unsolicited receipt of genetic information, such as "water cooler" conversations concerning a relative's illness, or information derived from such normative behavior as visiting the sick and consoling the bereaved. Legislative proposals should not impede employer efforts to protect the safety and well being of their employees through workplace wellness programs and other services currently allowed under state and federal law.

Today's genetic nondiscrimination legislation may quickly become outdated, and indeed counterproductive to its original purpose, unless it is drafted to avoid "unintended consequences" to the extent possible. The very information that is being censored today will very likely be the information that must be shared in a year or two to help someone delay the onset of disease or avoid it entirely. Yet, members of this Committee certainly are aware of how difficult it can be to "open up" controversial labor and employment laws to amendment even decades after enactment, based on fears of the law's original proponents that such amendments will be outside of their control. We are aware of the fact that proposals to amend the ADA may raise such fears, although a simple, straight-forward ADA amendment would be the most direct way of addressing

this issue. With reference to any genetic nondiscrimination legislation, we would suggest that one way to alleviate such fears, while avoiding "genetic exceptionalism," would be to incorporate ADA principles in a free-standing genetic nondiscrimination bill; and, one way to avoid the risk of legislation which becomes out-dated "before the ink is dry" is to mandate Congressional review or study of the legislation within a few years of its enactment.

We look forward to working with this Subcommittee, and other committees and Members of Congress on a bipartisan basis to address genetic nondiscrimination legislation. Members of the GINE Coalition commend the original sponsors of H.R. 602, the "Genetic Nondiscrimination in Health Insurance and Employment Act" – Representative Slaughter and Morella, and their staffs – who have worked hard over several Congresses to advance the promise of genetic research through their legislation. Although we have serious concerns causing us to oppose the current form of their legislation – especially its provisions for unlimited punitive and compensatory damages, and its lack of exhaustion requirements concerning ADA administrative procedures before the EEOC – we are hopeful that those and our other concerns as expressed later in this testimony can be addressed. We are aware that others in Congress may be considering the introduction of genetic nondiscrimination legislation. We welcome their efforts, as well which may enhance the likelihood of legislation being enacted.

We are well aware of President Bush's call for federal genetic nondiscrimination legislation that is "fair, reasonable, and consistent with other federal employment nondiscrimination statutes." We note, of course, that President Bush and members of his Administration are not late-comers to this issue. President Bush, then-Governor Bush, signed the Texas genetic nondiscrimination law in 1997; and, Health and Human Services Secretary Thompson, then-Wisconsin Governor

Thompson, signed the nation's first state genetic nondiscrimination law in 1991, long before the sequencing of the human genome. We look forward to working with President Bush, Secretary Thompson, and others in the Bush Administration on federal legislation, as well.

Finally, the members of the GINE Coalition recognize that legislation banning genetic discrimination in the workplace may help facilitate participation in clinical trials or encourage individuals to undergo medical tests or treatments to ensure their continued health. Because there appears to be a growing consensus for some form of protective federal legislation, if ever there was the opportunity for bipartisanship this is the issue and now is the time. We look forward to working with Congress and the White House, and with representatives of the disability and civil rights community in developing bipartisan legislation which can pass and be enacted into law.

The balance of our statement 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.

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 28 states – including six this year

– address in one form or another the issue of genetic discrimination in employment. (Attachment 2.) In addition, other state laws may address additional select aspects of genetic information.

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 an Policy Guidance explaining the definitions, Prohibitions, and exceptions in Executive Order 13145. (Attachment 3).

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 DISABILITES 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.

The EEOC has long taken the position that the Americans with Disabilities Act protects individuals with asymptomatic genetic conditions from discrimination in employment. EEOC's March 1995 Interpretative Guidance on the definition of "disability" under Title I of the ADA provides:

> "Covered entities that discriminate against individuals on the basis of genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of 'disability'." (Attachment 4).

Perhaps the best evidence that genetic information discrimination is already addressed by the ADA is the recent action that the EEOC filed against Burlington Northern-Santa Fe Railroad based on genetic testing of employees for a gene related to carpal tunnel syndrome after swift

government enforcement actions, the parties reached a settlement on the EEOC suit in April 2001, in which the railroad agreed to stop the test.

An employer's ability to engage in genetic testing and to use the results of such testing in making various types 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. § 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. Also, as stated above, while a person with a genetic marker or defect probably would not be considered as having an actual "disability," or a record of a "disability," as those term are defined under the statute, if an employer makes an employment decision based upon an individual's genetic characteristics, then the person may be able to claim that he or she was "regarded as" having a "disability" and, hence, covered under the provisions of the statute.

Limitations on Genetic Testing in the Workplace

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. § 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 that offer upon the successful completion of a medical examination. *Id.* at § 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 § 12112(d)(3)(A). Second, the information obtained must be collected and maintained in a confidential manner. 42 U.S.C. § 12112(d)(3)(B).[1] 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.* § 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. § 12112(b)(4)(A). This standard has been interpreted by the EEOC as relating to an employee's

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[1]The ADA authorizes disclosure of medical information obtained from a conditional medical examination only in the following circumstances:

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

42 U.S.C. § 12112(d)(3)(B)(i)-(iii).

present ability to perform the job. *See* 29 C.F.R. App. § 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, it remains problematic whether the ADA would allow genetic testing of current employees under the "job relatedness" standard.[2]

The current trend of judicial decisions recognizes that non-disabled individuals may enforce the statute's restrictions on medical inquiries.[3] Hence, even if an individual with a genetic marker or defect is not deemed to be "disabled" within the definition of the ADA, the statue still protects the person from being required to undergo genetic testing unless the testing complies with the above requirements.

Are Persons with Genetic Disorders "Disabled" Under the ADA?

Whether an individual with a genetic defect or trait would be considered "disabled" under the ADA, turns upon the specific definition of "disability" set forth in the statute. As discussed earlier, the ADA contains a three-part definition of the term. First, a person may be "disabled" if the individual has an impairment that substantially limits one or more major life activities. 42 U.S.C. § 12102(2)(A). A person with a genetic trait indicating that the individual has a predisposition to develop a certain type of disease or illness, such as breast cancer, sickle cell

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

[3]See *Cossette v. Minnesota Power & Light Co.,* 188 F.3d 964 (8th Cir. 1999); *Griffin v. Steel Tech, Inc.,* 160 F.3d 591, 594 (10th Cir. 1998); *Fredenburg v. Contra Costa County Dept.*

anemia, or Huntington's disease, in all likelihood, would not come under this first definition inasmuch as the individual has no present impairment that would substantially limit any major life activities. Rather, the individual has a genetic condition or marker indicating that, in the future, the person is likely to develop an impairment that would substantially limit a major life activity.[4]

The second part of the ADA definition covers individuals who have a record of an impairment that substantially limits a major life activity. 42 U.S.C. § 12102(2)(B). As noted above, a genetic defect or marker is an indication that an individual might develop a future impairment; it is not a marker or record of a past impairment. Hence, the "record of impairment" prong of the ADA definition of "disability" is not likely to lead to coverage under the ADA for individuals with genetic defects.

The ADA definition of disability, however, is not limited to an assessment of the individual's actual or past physical or mental condition. The third part of the ADA definition of "disability" – being "regarded as" having an impairment that substantially limits one or more major

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of Health Services, 172 F.3d 1176, 1182 (9th Cir. 1999).

[4]In light of the Supreme Court's decision in *Bragdon v. Abbott*, 524 U.S. 624 (1998), there has been some discussion as to whether or not an argument could be fashioned that genetic disorders may constitute actual disabilities under the statute. The *Bragdon* case involved an individual with asymptomatic HIV, whom the Supreme Court held was covered under the ADA because the person had an impairment that substantially limited her major life activity of reproduction. The Court's opinion, written by Justice Kennedy, emphasized that the term "asymptomatic" HIV, in reality, is a misnomer. From the moment of infection with the HIV virus, the body exhibits a number of medical symptoms, although those symptoms may be relatively few and not overtly manifest. Thus, even in the asymptomatic HIV stage, the virus still is thriving within a person's lymph nodes and is causing "immediately abnormalities in a person's blood." 118 S.Ct. at 224. A person with a genetic disorder may exhibit no such abnormalities and, hence, as a practical matter would not be considered to have any actual physical impairment. Thus, the reasoning that the Supreme Court used to classify HIV-positive individuals, even those with asymptomatic HIV, as disabled may not be applicable to individuals possessing genetic indications of disease.

life activities – focuses upon the attitude and perceptions of others. *Id.* § 12102(2)(C). Thus, an individual with no actual or record of an impairment still may be deemed to be "disabled" under the ADA if other persons perceive or regard that individual as having an impairment that would substantially limit a major life activity.

As noted earlier, the EEOC in its March 1995 Interpretative Guidance on the definition of "disability" under the ADA, stated that genetic discrimination could be covered under the "regarded as" prong of the ADA definition of disability.[5] Thus, for example, if an employer refuses to employ an individual with a genetic marker or defect that indicates the likelihood of the individual developing breast cancer, it may be argued that the employer has perceived the individual as having an impairment that substantially limits the major life activity of working.[6]

Importantly, the EEOC has recognized that an employer's perception that an individual may not be able to perform a particular job does not necessarily mean that the individual has been regarded as being disabled. The employer's perception must limit the person in a broad range or class of jobs. 29 C.F.R. App. § 1630.2(j). Thus, if an employer determined that a job applicant with a genetic defect or marker indicating susceptibility to cancer could not work in a particular job involving the use of cancer-causing chemicals, the employer would not have regarded the person as being disabled. If the employer perceived the person as being limited from performing only one particular type of work – not from working in general – the employer may not have

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[5]EEOC Compliance Manual (BNA), 902.8(a) (1995).

[6]The EEOC has taken the position that "working" may be a major life activity. 29 C.F.R. § 1630.2(i). However, in *Sutton v. United Air Lines*, 527 U.S. 471 (1999), Justice O'Connor, writing for the majority, called into question the deference that should be accorded to the EEOC's position.

regarded the individual as being "disabled." On the other hand, if the employer refuses to employ the individual with the genetic defect based upon the perception that the person was disqualified not only from working with particular chemicals, but also from working in any job, then the employer regarded the individual as substantially limited in the major life activity of working and, hence, as "disabled."

It may be said that the third prong of the ADA's definition of disability – being regarded as having a disability – produces a number of anomalies because an employee or job applicant with a genetic defect may or may not be covered by the statute depending upon the subjective views of the employer. In one circumstance, the individual may be deemed disabled, but in another situation with a different employer, the person may not be able to establish statutory coverage. What may seem to be an anomaly in the legislation, however, actually is a result consistent with the purposes of the ADA, which is to prohibit discrimination on the basis of "disability," not necessarily on the basis of an individual's health condition. As the Supreme Court recognized; in *Sutton v. United Air Lines*, Congress passed the ADA to prohibit discrimination against a particular segment of our society – persons with disabilities – who have been shut out of the opportunities available to the majority of so-called able-bodied persons.

In general, therefore, under the "regarded as" prong of the ADA, employers must not make employment decisions involving individuals with genetic disorders based upon myths, fears, or stereotypes, but rather upon the person's ability to perform specific required job tasks, with or without reasonable accommodation, in a safe manner.[7]

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[7]We should recognize, however, that there may be perfectly valid and non-discriminatory reasons for an employer to consider an employee's genetic information in order to ensure that the

THE GENETIC NONDISCRIMINATION IN HEALTH INSURANCE AND EMPLOYMENT ACT, H.R. 602.

We have no disagreement in principle with providing employment protection for individuals on the basis of genetic information. The issue is how best to achieve that goal without at the same time creating an overly broad, litigation-driven system, when a narrower, privacy-oriented approach might suffice, at least initially until there is some greater empirical evidence that a problem exists calling for a more stringent approach.

Based on my experience in counseling employers with regard to the existing plethora of workplace laws and regulations, we cannot recommend to Congress the path of "genetic exceptionalism" through the enactment of an employment discrimination law, with unlimited punitive and compensatory damages and a unique remedial scheme, when adequate remedies already exist under the Americans with Disabilities Act and other state or federal employment discrimination laws.

We are especially concerned about the potential for litigation abuse which may arise under this legislation. We have all witnessed the unintended legal consequences of well-intentioned workplace laws, where employers who cannot win a lawsuit on summary judgment because of

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employee is working in an environment that would not exacerbate the employee's genetic predisposition to an illness or other health condition. The ADA recognizes that an employer may impose the qualification standard that an employee not pose a "direct threat" to the health or safety of others in the workplace. 42 U.S.C. § 12113(b). The EEOC has expanded this statutory definition to include the individual with a disability. 29 C.F.R. § 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. Recently, however, in *Echazabal v. Chevron*, 2000 U.S. App. LEXIS 11399 (9th Cir. May 23, 2000), the Ninth Circuit refused to interpret the direct threat standard as being applicable to the health or safety of the individual.

material factual issues in dispute are forced to settle employment discrimination claims at all costs to avoid potentially adverse jury verdicts and excessive damage awards. We are concerned that this legislation, with its overly broad definition of genetic information and open-ended liability for unlimited compensatory and punitive damages, may actually serve to foster litigation and workplace disputes. We believe that is not the sponsors' intention.

Why then should the legislation avoid the EEOC's procedures of testing the sufficiency of employment discrimination charges prior to litigation, and instead allow claimants of genetic discrimination to proceed directly into court? Why should claimants with genetic discrimination charges be entitled to punitive and compensatory damages greater than those available to most other claimants of employment discrimination, including those who are actually disabled? Why is there no time limitation on the filing of an action, as there is for charges filed with the EEOC under other employment discrimination laws? Why is there no "safe harbor" protection from liability, or other defense for employers who inadvertently receive genetic information, for example in routine health insurance claims, or who innocently receive unsolicited information concerning family histories? Is such employer presumptively held strictly liable for any adverse employment action even for cause or based on performance? Certainly in the eyes of a jury, and without the filter of an agency such as the EEOC to screen non-meritorious charges, the employer will be hard pressed to demonstrate that the information was not an unlawful factor in the employment decision, especially a decision involving an individual with a life-threatening genetic marker who is likely to evoke the sympathy of a jury.

One thing we are regularly told by GINE Coalition members is that, above all, they want certainty and consistency in the application of labor and employment laws, and they want a clear

understanding as to their legal obligations under such laws. It seems to us that creating conflicting standards and competing forums for genetic discrimination will only confuse and impede both the administration and enforcement of those laws.

In that regard, the legislation should provide clearer definitions. For example, as currently drafted, it would appear that H.R. 602 prohibits employers from the mere receipt or possession of "protected" genetic information, as broadly defined. We are concerned and somewhat confused by the term "protected" genetic information in H.R. 602, when last year's bill used the term "predictive" genetic information – a term commonly used and well understood in the scientific community. We are also concerned that such information includes not only the employee's own "genetic tests" or those of family members, but also any "information about the occurrence of a disease or disorder in family members" Sec. 201(6)(A)(iii). This overly broad definition disregards the nature of the "disease" and how far removed or consanguineous the "family member."

A practical, real world concern among employers is whether such broad proscriptions would trigger litigation based on mere knowledge of an employee's family disease or disorder which may come to the employer's attention through unsolicited genetic information in routine medical reports, leave requests, or even through on-the-job or off-the-job social conversations, newspaper obituaries, and the like, where family illnesses or causes of death may be discussed. Certainly, it is not uncommon for employees to share family problems with co-workers, supervisors, and business owners, or even to seek their assistance in times of trouble, especially in small business workplaces. Once an employer is invested with such knowledge, does that then serve as the basis for litigation arising from any subsequent adverse employment decision, where

the employer must attempt to convince a jury that knowledge of the genetic information was not a factor in the decision? Faced with unlimited punitive and compensatory damages, it is understandable that an employer may seek to enter into an expensive settlement agreement simply to avoid a potential run-away jury award. The law then becomes a "sword" for trial lawyers rather than a "shield" for employees. And, under H.R. 602, as drafted, the litigation sword could potentially be wielded in multiple forums based on information received from normative human behavior – visiting the sick and consoling the bereaved – that our traditions, social mores, and laws should encourage.

These are a few of the issues we hope will be addressed by this Committee in its consideration of H.R. 602.

CONCLUSION

Genetic information should not be used as the basis for employment discrimination. There is no disagreement on that principle. Although there is no empirical evidence of widespread genetic discrimination in employment, federal legislation may be necessary to alleviate employees' fears that genetic information will be used for discriminatory purposes in the workplace. Any federal legislation prohibiting genetic discrimination in employment should conform to other federal employment discrimination laws, and should focus on controlling discriminatory conduct, not posession of information. Such legislation should not be so broadly constructed as to encourage frivolous litigation.

The remarkable advances of the Human Genome Project should be the source of hope for the world's population, not of fear or anxiety that such information will be misused. Individuals should be encouraged to participate in genetic testing and clinical trials without concern that, as a result, they may suffer loss of privacy or loss of employment. Absent such assurances, we may experience the ultimate irony: opening the book of life, but with no one willing to take advantage of its teachings.

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Harold P. Coxson, Jr.

	Yes	No
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).		X

2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998:

NONE

	Yes	No
3. Will you be representing an entity other than a government entity?	X	

4. Other than yourself, please list what entity or entities you will be representing:

Genetic Information Non-Discrimination in Employment (GINE) Coalition (a business coalition, including the Society for Human Resource Management, U.S. Chamber of Commerce, National Association of Manufacturers, and College and University Professional Association for Human Resources.

5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4:

Counsel to GINE Coalition.

6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract:

NONE

	Yes	No
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:		X

Signature: Harold P. Coxson Date: 7/20/01

Please attach this sheet to your written testimony.

PERSONAL INFORMATION: Please provide the committee with a copy of your resume (or a curriculum vitae). If none is available, please answer the following questions:

a. Please list any employment, occupation, or work related experiences, and education or training which relate to your qualifications to testify on or knowledge of the subject matter of the hearing:

Member, Employment Issues Committee, National Conference of State Legislatures' Blue Ribbon Panel on Human Genetic Technologies; Management Attorney, with 25+ years experience specializing in labor and employment law, including counseling employers in administrative and court litigation.

b. Please provide any other information you wish to convey to the Committee which might aid the members of the Committee to understand better the context of your testimony:

NONE

Please attach to your written testimony.

Ogletree Deakins
ATTORNEYS AT LAW

2400 N Street, N. W.
Fifth Floor
Washington, DC 20037
Telephone: 202.887.0855
Toll Free: 800.899.0855
Facsimile: 202.887.0866
hal.coxson@odnss.com

Practice Areas:

U.S. and International Labor and Employment Law, Workplace Legislation, Trade and Professional Associations, Alternative Dispute Resolution

Education:

J.D., American University Law School (Law Review Managing Editor), 1972
B.A., Franklin & Marshall College, 1969

Admitted to Practice:

State of New Jersey, 1972
District of Columbia, 1981

Professional Activities:

U.S. Employer Advisor, ILO's Governing Body and International Labor Conference, 1980-1985
Employer Representative, President's Tripartite Advisory Panel on International Labor Standards, 1980-1988
Member, Management Lawyers Advisory Panel, National Labor Relations Board
Member, National Conference of State Legislatures' Blue Ribbon Panel on Human Genetic Technologies (Employment Issues Committee)
Chairman, Subcommittee on Workplace Trends and International Perspectives, U.S. Chamber of Commerce
Member, Committee on Employment Law, National Retail Federation
Labor Law Attorney, 1975-1977 and Director of Labor, 1977-1980, U.S. Chamber of Commerce
Attorney, Appellate Section, Office of the Solicitor, U.S. Department of Labor, 1972-1975
Bar Association of the District of Columbia
American Bar Association (Chairman, Labor Law Committee, International Law Section, 1986-1987)

Personal:

10/26/47 (Camden, NJ); married, 3 children and 1 grandchild; resident of Washington, D.C.

Position:

Shareholder, Ogletree Deakins
Principal, Ogletree Governmental Affairs, Inc.

Harold P. Coxson, Jr.

Mr. Coxson has over 25 years experience in all aspects of workplace law. He has represented business clients in oral arguments before the National Labor Relations Board and other federal administrative agencies; litigated important labor and employment cases in the federal courts; and helped shape national workplace law and policy through oral arguments and the filing of amicus curiae briefs on behalf of business clients in several landmark cases before the federal courts of appeals and U.S. Supreme Court. In addition, he has counseled employers in various aspects of labor and employment law, including methods of avoiding workplace litigation through alternative dispute resolution. He has represented businesses in union representation and unfair labor practice cases, as well as domestic and international "corporate campaigns."

Mr. Coxson has been appointed by the NLRB as a member of its Management Lawyers Advisory Panel. In addition, he is an appointed member of the Employment Issues Committee of the National Conference of State Legislatures' Blue Ribbon Panel on Human Genetic Technologies.

Mr. Coxson is a Principal in Ogletree Governmental Affairs, Inc., a subsidiary of Ogletree Deakins. In his government relations practice, Mr. Coxson is an advocate for the business community before Congress and the Executive Branch. He represents individual corporations and national trade associations, as well as business coalitions which he has been responsible for organizing on a variety of workplace issues over the past quarter century.

He has a close working relationship on labor and employment law issues with many of the national trade associations in Washington. Mr. Coxson currently serves as the chairman of the U.S. Chamber's Subcommittee on Workplace Trends and International Perspectives and as a member of its Labor Relations Committee. He is a member of the National Retail Federation's Committee on Employment Law. He is a past chairman of the National Association of Manufacturers' Employment Lawyers' Advisory Committee. He also serves as Executive Director of the First Tuesday Group, an organization of twenty-seven national trade associations involved in workplace issues.

Mr. Coxson brings to his legislative responsibilities a practitioner's perspective, having counseled employers and practiced labor and employment law before courts and administrative agencies. In addition, he

brings an international perspective, having been appointed for many years as a labor law advisor and member of the U.S. Employer delegation to the Governing Body and International Labor Conferences of the U.N.-sponsored International Labor Organization (ILO) in Switzerland. He also has served as the Employer Member of the President's Tripartite Advisory Panel on International Labor Standards.

ATTACHMENT 1

Genetic Information Non-Discrimination in Employment (GINE) Coalition

Background:

The recent completion of the Human Genome Project has resulted in the identification of numerous genes responsible for various medical conditions. Access to this important information holds great promise for the early detection, treatment, and prevention of many human diseases. Yet, at the same time many legal concerns have surfaced about the potential misuse of genetic information. Concern exists that individuals who have a predisposition to certain diseases or conditions, or with medical conditions in their family background, may find themselves at a risk of being stigmatized as an economic or safety risk for employment; may face discrimination in employment decisions; or may be hesitant to seek treatment or participate in genetic research for fear of employer reprisal. Policymakers are seeking to prevent genetic discrimination in the workplace by prohibiting the collection and usage of employee genetic information for hiring, advancement, or compensation decisions, as well as provide a new remedial scheme for individuals alleging genetic discrimination.

Despite the fact that there is no evidence to suggest widespread possession or usage of genetic information by employers, legislation may be needed to codify current protections against genetic discrimination offered by the Americans with Disabilities Act (as articulated by the EEOC's 1995 Guidance on Disability), as well as to fill the gaps left unaddressed by current law. Legislation banning genetic discrimination in the workplace may help facilitate participation in clinical trials or encourage individuals to undergo medical tests or treatment to ensure their continued health.

Coalition Principles:

The Genetic Information in the Workplace 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 discriminate, remedies should be available. However, the coalition would oppose legislation that

would provide unlimited punitive and compensatory damages for victims of genetic discrimination.

- All other anti-discrimination laws limit damage awards. While it is critical to protect those who truly have been discriminated against, these individuals should be covered by the same protections and offered the same remedies under the law as do individuals affected by all other types of workplace discrimination.

- Legislative proposals should not impede employer efforts to protect the safety and well being of their employees through workplace wellness programs and other services currently allowed under state and federal statutes.

- The Genetic Information in the Workplace Coalition is working with employers and other stakeholders to draft legislation outlawing genetic discrimination in a way that protects employees AND employers.

ATTACHMENT 2

State Genetic Nondiscrimination in Health Insurance Laws

Genetic Technologies Project
NCSL Genetics Tables

State Genetic Nondiscrimination in Health Insuranc

Last updated: 7/20/01

A patchwork of federal and state laws govern discrimination based on genetic information for health insurance. T endorses the primacy of state insurance regulation. The Employees Retirement Income Security Act of 1974 pre employee benefits plans. The Health Insurance Portability and Accountability Act of 1996 became the first federal The law prohibits health insurance discrimination based on any "health status-related factor," including genetic inf with more than 50 individuals.

States have acted to fill in the gaps left by HIPAA. Laws in 34 states strictly prohibit the use of genetic information purposes. Additionally, Arizona, Maine, Massachusetts, Oklahoma, Vermont, and West Virginia require actuarial j Texas bans use of genetic information in group health plans, and Alabama prohibits discrimination based upon pr

State	Citation	Type of Insurance Policy	May not Establish Rules for Eligibility based on Genetic Information	May not Seek Genetic Information	May not U Genetic Informatio for Risk Selection Risk Classificati Purposes
Alabama	§§27-53-1 to 4, 13	Individual and Group	1		1
Alaska	§§21.54.100, 110	Group			2
Arizona	§§20-448, 448.02	Individual and Group	4		3
Arkansas	23§§86-304, 305, SB763	Group			2
California	Insurance Code: §§742.405, 7, 10140, 3, 6 to 9, 9.1	Individual and Group			
Colorado	§10-3-1104.7	Individual and Group			
Connecticut	38a§§816,	Individual and			

State Genetic Nondiscrimination in Health Insurance Laws

	476	Group			
Delaware	§§16-1220, 18-2317	Individual and Group			
Florida	§§627.4301, 627.6419, 636.0201, 641.31071, 641.31073, 641.438, 760.40	Individual and Group			
Georgia	§§33-54-1 to 8	Group or Individual			
Hawaii	§§431-10a-118, 432-1-607, 432d-26	Individual			
Idaho	§§41-2221, 41-3940, 41-4708	Group			
Illinois	215-97/20, 97/25, 410-513/10 to 45	Individual and Group			2,4
Indiana	27§§4-1-4 (23), 8-26-1 to 11	Individual and Group			4,5
Iowa	§513b.9a, 10 (4)(a)(1)	Group			2
Kansas	§40-2259	Individual and Group			
Kentucky	§§304.12-085, 304.17a-200, 220, 230, 320	Individual and Group			
Louisiana	22§213.7	Individual and Group			
Maine	24A§§2159-C(2), 2204, 2850-C, 22§1711-C	Individual and Group			3
Maryland	Ins §27-208, 909	Individual and Group			6
Massachusetts	111§70G; 175§120E; 176§3B; 176B§5B; 176G§24; 176I§4A	Individual and Group			3, 4
Michigan	§§550.1401, 3407(b)	Individual and Group			

State Genetic Nondiscrimination in Health Insurance Laws

	3407(b)	Group			
Minnesota	§72a.139	Individual and Group			
Mississippi					
Missouri	§§375.1300 to 12	Individual and Group			4
Montana	§§33-18-901 to 903	Individual and Group			6
Nebraska	§§44-787, 524.02, 6910, 15, 16	Individual			
Nevada	§§689a.417, 689b.069, 689c.076, 198	Individual and Group			
New Hampshire	§§141-H:1, 2, 4, 6	Individual and Group			
New Jersey	10:5-43 to 49, §17B:30-12	Individual and Group			
New Mexico	§§24-21-1 to 7	Individual and Group		4	4
New York	Ins §2612	Individual and Group		4	4
North Carolina	§§58-3-25, 215	Group			
North Dakota	§§26.1-36.3-01, 06, 26.1-36.4-03.1	Group			
Ohio	§§1751.65, 3901.49, 50	Individual and Group			
Oklahoma	§36-3614.1	Individual and Group			3
Oregon	§746.135	Individual and Group		4	6
Pennsylvania					
Rhode Island	§§27-18-52, 19-44, 20-39, 41-53, HB 5347, SB 0803	Individual and Group			
South Carolina	§§38-93-10 to 60	Individual and Group			
South Dakota	§§58-18-45,	Group			

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State Genetic Nondiscrimination in Health Insurance Laws

	58-18B-27				
Tennessee	§§56-7-2701 to 08	Individual and Group			
Texas	Ins §21.73	Group			[6]
Utah					
Vermont	§§8:4724, 18:9334	Individual and Group			[3]
Virginia	§§38.2-508.4, 613	Individual and Group			
Washington					
West Virginia	§§33-15-2 (a), Individual			[3]	
Wisconsin	§§631.89, 632.746, 8	Individual and Group			
Wyoming	§26-19-102 (g), 22-502	Group			

NOTES:
"GT" indicates individual genetic test results
"GF" indicates genetic test results of family members
"AC" indicates practices commonly accepted in scientific and medical communities
'FH" indicates family history
"IC" indicates inherited characteristics
"RP" indicates routine physical measurements
"CA" indicates standard chemical, blood, and urine analyses
"IM" indicates indirect manifestations of genetic disorders

[1]Alabama only prohibits the use of genetic information for denying coverage for applicants with sickle cell anemia for cancer in risk selection or risk classification.

[2]Prohibits the use of genetic information for the establishment of a premium, contribution, or policy fee greater th in the plan on the basis of a health status factor.

[3]Prohibits the use of genetic information without actuarial justification.

[4]Permits the use of genetic information only when voluntarily submitted.

[5]Permits the use of genetic information only when favorable to the individual.

[6]Prohibits the use of an individual's genetic information to increase his policy rates.

Source: NCSL, June 2001
For additional information, please contact:
Cheye Calvo, Alissa Johnson, Erica Knievel
NCSL, Employment and Insurance Program
(303) 830-2200

State Genetic Nondiscrimination in Employment Laws

NCSL Genetics Tables

State Genetic Nondiscrimination in Employment La

Last updated: 7/13/01

Several states acted against employer use of genetic information in the 1970s and '80s to prohibit employer discr with the sickle cell trait. Wisconsin was the first state to ban genetic testing and discrimination in the workplace in Louisiana, Maryland, Minnesota, Nebraska, and South Dakota enacting measures in 2001, genetic nondiscrimina in place in 28 states. The scope and functions of these laws vary widely. All laws prohibit discrimination based on many extend the protections to information related to genetic testing, and some include test result of family memb inherited characteristics. Most states also restrict employer access to genetic information, with some prohibiting e requiring and obtaining genetic information, or directly or indirectly performing or administering genetic tests.

On the federal level, the Equal Employment Opportunity Commission in 1995 interpreted "disability" in the Americ include genetic predisposition to disease, but conflicting rulings raise questions whether the Supreme Court woul interpretation. President Clinton in February 2000 banned genetic discrimination in the federal workplace and call federal genetic information nondiscrimination law for private sector employment. The U.S. Senate debated the m 2000, but took no action.

State and Statute	Genetic Nondiscrimination Covers				Genetic discrimination prohibited in hiring, firing, and/or terms, conditions or privileges of employment	Prohibits Employer		
	Genetic Test Results	Information About Genetic Testing	Family History	Inherited Characteristics		Requesting Genetic Information	Requiring Genetic Information	Pe form Gen Te
Total	28	9	9	10	28	17	20	1
Alabama								
Alaska								
Arizona §41-1463	√				√			
Arkansas SB766	√				√	√	√	√
California Govt. §12926, Govt. §12940	√		√	√	√			√
Colorado								
Connecticut §46a-60	√		√	√	√	√	√	
Delaware §19-710 to 711	√				√			
D.C.								
Florida								
Georgia								

State Genetic Nondiscrimination in Employment Laws

Hawaii								
Idaho								
Illinois §410-513/25, 215 ILCS 5/356v	√				√			
Indiana								
Iowa §729.6	√				√	√	√	
Kansas §44-1002, §44-1009	√				√	√	√	√
Kentucky								
Louisiana SB651	√	√	√		√	√	√	
Maine §5-19301, §5-19302	√	√	√	√	√	√	√	
Maryland HB18, SB2	√			√	√	√	√	
Massachusetts §151B	√	√	√	√	√	√	√	√
Michigan §37.1201, §37.1202	√		√		√		√	√
Minnesota SF1721	√	√			√	√	√	√
Mississippi								
Missouri §375.1300, §375.1306	√				√			
Montana								
Nebraska LB432	√				√		√	
Nevada §613.345	√				√	√	√	√
New Hampshire 141-H:3	√				√	√	√	√
New Jersey §10:5-5, §10:5-12	√	√	√	√	√			
New Mexico								
New York Exec §292, Exec §296	√				√	√	√	√
North Carolina §95-28.1A	√	√	√	√	√			
North Dakota								
Ohio								
Oklahoma §36-3614.2	√				√	√	√	√
Oregon §659.036	√				√	√	√	√
Pennsylvania								
Rhode Island								

http://www.ncsl.org/programs/health/genetics/ndiscrim.htm 7/22/01

State Genetic Nondiscrimination in Employment Laws

Rhode Island §28-6.7-1	√	√		√	√	√	√	√
South Carolina								
South Dakota SB2	√		√	√	√	√		
Tennessee								
Texas §21.402	√				√		√	
Utah								
Vermont §18-9333	√	√		√	√		√	√
Virginia								
Washington								
West Virginia								
Wisconsin §111.372	√	√			√	√	√	√
Wyoming								

Source: NCSL
For additional information, please contact:
Cheye Calvo, Alissa Johnson
NCSL, Employment and Insurance
(303) 830-2200

National Conference of State Legislatures
INFO@NCSL.ORG (autoresponse directory)

Denver Office:
1560 Broadway, Suite 700
Denver, CO 80202
Tel: 303-830-2200
Fax: 303-863-8003

Washington Office:
444 North Capitol Street, N.W., Suite 515
Washington, D.C. 20001
Tel: 202-624-5400
Fax: 202-737-1069

State Genetic Summary Table on Privacy Laws

NCSL Genetics Tables

State Genetic Privacy Laws

Last updated: 7/9/01

Medical information is presumed confidential, but increasing capabilities to store and rapidly transfer data escalat challenge of protecting privacy. Laws in all states restrict access to medical records. At issue is whether genetic information should be protected generally, as another component of health data, or by special genetic privacy law

The case against "genetic exceptionalism" asserts that genetic information is fundamentally no different than othe health data and special protections for one type of information could deny safeguards that should be established generally. Proponents argue that the stability of genetic information and unique predictive – rather than merely hi - qualities warrant special consideration.

Laws in 14 states require informed consent for a third party to perform or require a genetic test or obtain genetic information. Twenty-two states require informed consent to disclose genetic information. Colorado, Florida, Geor Louisiana and Oregon explicitly define genetic information as personal property. Oregon extends the property rig DNA samples. Four states mandate individual access to personal genetic information, and 16 states establish sp penalties – civil or criminal – for violating genetic privacy laws.

State and Statute	Personal Access to Genetic Information Required	Informed Consent Required to				Define as Personal Property		Spe Pena fo Gen Priv Violat
		Perform or Require Genetic Test	Obtain Genetic Information	Retain Genetic Information	Disclose Genetic Information	Genetic Information	DNA Samples	
Alabama								
Alaska								
Arizona §20-448.02		√			√			
Arkansas SB764					√			
California Insurance §10149.1					√			√
Colorado §10-3-1104.7					√	√		√
Connecticut								
Delaware §16.2.1220 to §16.2.1227	√		√	√	√			√
Florida §760.40		√			√	√		√
Georgia §§33-54-1 to 8		√			√	√		√

State Genetic Summary Table on Privacy Laws

Hawaii								
Idaho								
Illinois §410-513					√			√
Indiana								
Iowa								
Kansas								
Kentucky								
Louisiana §22:213.7; §40:1299.6					√	√		√
Maine								
Maryland								
Massachusetts §111.70G		√			√			√
Michigan §333.17020 §333.17520		√						
Minnesota								
Mississippi								
Missouri §375.1309					√			√
Montana								
Nebraska								
Nevada §629.101 to §629.201	√		√	√	√			√
New Hampshire §141-H:2					√			
New Jersey §10:5-43 to §10:5-49			√	√	√			√
New Mexico §24-21-1 to §24-21-7	√	√	√	√	√			√
New York CVR §79-L		√		√	√			√
North Carolina								
North Dakota								
Ohio								
Oklahoma								
Oregon §659.700, §659.715	√		√	√	√	√	√	√
Pennsylvania								
Rhode Island HB5347, SB803					√			
South Carolina §38-93-10 to §38-93-60		√			√			√
South Dakota SB1		√						
Tennessee								
Texas Vernon's Civil §9031					√			

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State Genetic Summary Table on Privacy Laws

Utah								
Vermont §18:9331 to §18:9335		√			√			√
Virginia §38.2-508.4					√			
Washington								
West Virginia								
Wisconsin								
Wyoming								
Total	4	10	5	6	22	5	1	1

Source: NCSL
For additional information, please contact:
Cheye Calvo
Alissa Johnson
NCSL, Employment and Insurance
(303) 830-2200

National Conference of State Legislatures
INFO@NCSL.ORG (autoresponse directory)

Denver Office:
1560 Broadway, Suite 700
Denver, CO 80202
Tel: 303-830-2200
Fax: 303-863-8003

Washington Office:
444 North Capitol Street, N.W., Suite 515
Washington, D.C. 20001
Tel: 202-624-5400
Fax: 202-737-1069

ATTACHMENT 3

Policy Guidance on Genetic Testing

The U.S. Equal Employment Opportunity Commission

		Number
EEOC	*NOTICE*	915.002
		Date
		7/26/00

1. SUBJECT: EEOC Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information

2. PURPOSE: This policy guidance explains the definitions, prohibitions, and exceptions in Executive Order 13145.

3. EFFECTIVE DATE: Upon receipt.

4. EXPIRATION DATE: As an exception to EEOC Order 205.001, Appendix B, Attachment 4, § a(5), this Notice will remain in effect until rescinded or superseded.

5. ORIGINATOR: Coordination Division, Office of Legal Counsel.

6. INSTRUCTIONS: File after Section 902 of Volume II of the Compliance Manual.

7/26/00
Date

/s/
Ida L. Castro
Chairwoman

DISTRIBUTION: CM Holders

Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic

Policy Guidance on Genetic Testing

Information

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Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information

I. INTRODUCTION

On February 8, 2000, President Clinton signed Executive Order 13145, which prohibits discrimination on the basis of protected genetic information in the Executive branch.(1) The President expressed the hope that the Executive Order would "set an example and pose a challenge for every employer in America" to adopt a policy not to discriminate on the basis of protected genetic information, "because . . . no employer should ever review your genetic records along with your resume."(2)

Executive Order 13145 is intended to ensure that Executive branch applicants and employees are judged on their current ability to perform the jobs they seek or hold, and not on the possibility that they might, some day, develop a disease or condition. Accordingly, the Executive Order places stringent limits on the collection, use, and disclosure of protected genetic information.

The Executive Order assigns to the U.S. Equal Employment Opportunity Commission (EEOC or

Commission) the responsibility for coordinating "the policy of the Government of the United States to prohibit discrimination . . . based on protected genetic information, or information about a request for or the receipt of genetic services."[3] The EEOC is issuing this Policy Guidance to:

- explain what type of genetic information is covered by the Executive Order;
- give examples of how the Executive Order affects the collection, use, and disclosure of protected genetic information in Executive branch employment; and
- explain how an individual can establish that s/he has a disability under section 501 of the Rehabilitation Act of 1973, as amended,[4] based on protected genetic information.

II. BACKGROUND

Relationship to the Rehabilitation Act / Americans with Disabilities Act

The Executive Order does not create any new enforceable rights for Executive branch applicants and employees. As more fully discussed in this Guidance, applicants and employees who believe that a department or agency has violated the Executive Order by discriminating on the basis of protected genetic information may be able to establish coverage under section 501 of the Rehabilitation Act (section 501, the Rehabilitation Act, or the Act).

In 1992, Congress amended section 501 to apply the standards of Title I of the Americans with Disabilities Act (ADA) to all complaints of non-affirmative action employment discrimination.[5] The Commission has issued regulations and enforcement guidances that interpret and provide Commission policy under the ADA. This Policy Guidance will cite to ADA regulations and enforcement guidances when they are relevant to the Executive Order or the Rehabilitation Act.

Coverage

The Executive Order directs Executive departments and agencies to extend the policy of nondiscrimination based on protected genetic information to all its employees.[6]

III. DEFINITIONS IN THE EXECUTIVE ORDER

1. *How does the Executive Order define **protected genetic information**?*

   Protected genetic information includes:

   - information about an individual's **genetic tests**;
   - information about the **genetic tests of an individual's family members**; or
   - information about the occurrence of a disease, or medical condition or disorder in family members of the individual (**family medical history**).[7]

2. *What is the Executive Order's definition of a **genetic test**?*

   A genetic test includes the "analysis of human DNA, RNA, chromosomes, proteins, or

certain metabolites in order to detect disease-related genotypes or mutations."[8] The Executive Order refers to RNA, chromosomes, proteins, and metabolites to make clear that genetic tests include not only examination of the DNA itself but also of other substances that provide information about the condition of an individual's DNA.

3. *Why is **family medical history** considered "protected genetic information"?*

   In an employment context, family medical history does not provide information about an individual's **current ability to do the job**. Therefore, family medical history, like genetic test results, should not be used for employment decisions.

4. *Does "protected genetic information" include information about an applicant's or an employee's **current health status**?*

   Generally, no. Information about an applicant's or employee's **current health status**, which under the Executive Order includes information about sex, age, physical exams, and chemical, blood, or urine analyses, generally is not considered protected genetic information.[9] If, however, the department or agency obtains protected genetic information when seeking current health status information, the Executive Order states that the protected genetic information will be subject to the same restrictions that apply to protected genetic information generally.[10]

   Although the Executive Order permits departments or agencies to obtain current health status information, the Rehabilitation Act and other applicable laws may limit a department's or agency's right to request or require a medical examination, including chemical, blood, or urine analyses. As discussed below, in response to Questions 8 and 11, the Rehabilitation Act regulates disability-related inquiries and medical examinations of applicants and employees.[11]

5. *How does the Executive Order define **genetic monitoring**?*

   Genetic monitoring is the periodic medical examination of employees to determine whether any of their genes have been affected by the toxic substances they use or are exposed to in performing their jobs. Genetic monitoring enables an employer to deal with the effect of workplace toxins and to attempt to control their effect on employees.[12] The requirements applicable to genetic monitoring are discussed in response to Question 15.

6. *How does the Executive Order define **genetic services**?*

   Genetic services are health services, including genetic tests, provided to obtain or interpret genetic information for diagnostic or therapeutic purposes, or for purposes of genetic education or counseling.[13] The conditions under which a department or agency may obtain protected genetic information when providing genetic services are discussed in response to Question 13.

IV. PROHIBITIONS UNDER THE EXECUTIVE ORDER

The Executive Order directs departments and agencies to implement several nondiscrimination requirements. Under the Executive Order, departments and agencies **must not**:

- engage in adverse employment actions on the basis of protected genetic information or information about a request for, or the receipt of, genetic services;
- request, require, collect, or purchase protected genetic information about employees, with limited exceptions;
- maintain protected genetic information in general personnel files, rather than in confidential medical files; or
- disclose protected genetic information about employees, except in limited circumstances. (14)

This section discusses all of these prohibitions except the prohibition on collecting protected genetic information, which is best understood in light of its limited exceptions explained in Section V, below.

Adverse Employment Actions Based on Protected Genetic Information

The Executive Order states that the policy of the federal government is to provide equal employment opportunity to all qualified persons. Federal policy prohibits a department or agency from discharging, failing to hire, or otherwise discriminating against a covered individual with respect to the individual's compensation and terms, conditions, and privileges of employment based on the person's "protected genetic information," or the person's request for, or receipt of, genetic services. Federal policy also prohibits a department or agency from limiting, segregating, or classifying its employees based on protected genetic information.

This policy applies to every aspect of employment in the Executive branch.

> ***Example A*** : Lisa works for a federal agency in a non-managerial position. Lisa's supervisor, Karen, learns that she took part in a breast cancer study that included genetic testing. Lisa has expressed an interest in, and is qualified for, a detail to another position that the agency views as career-enhancing. If Karen were to deny Lisa's request for the detail based on her participation in the breast cancer study, she would be acting in violation of the Executive Order. Karen would be limiting Lisa's employment opportunities based on her receipt of genetic services.
>
> ***Example B***: Tonya learns that David's father died recently of pancreatic cancer and that David's brother is seriously ill with the same disease. David is a well-respected and highly-rated subordinate employee in Tonya's research division. Budget cuts to the division will require layoffs, and Tonya will lose two employee slots. If Tonya decides to identify David's slot for elimination based on his family history of cancer, she will be violating the Executive Order.

Confidentiality of Protected Genetic Information

Under the Executive Order, departments and agencies must **assure the confidentiality** of any protected genetic information that they collect. This information must be treated with the same care as other confidential medical information and must be kept in files that are maintained

separately from official personnel files.[15]

The Rehabilitation Act also requires that applicant and employee medical information be kept confidentially in separate files.[16]

Disclosure of Protected Genetic Information

The Executive Order permits disclosure, in limited circumstances, of protected genetic information and of information about an employee's request for or receipt of genetic services.[17] These narrow exceptions permit disclosure only:

- to the employee;
- to a person conducting research that complies with 45 C.F.R. Part 46, which concerns research involving human subjects;
- if required by federal law;
- in response to a congressional subpoena or an order from a court with competent jurisdiction;[18] or
- to Executive branch officials investigating compliance with the Executive Order.

Example C: During a post-offer medical examination, Richard informs the agency's medical office of a family medical history of a genetic-based disorder with clinical indications that include seizures. Richard reports that he has been diagnosed with this disorder and recently had a seizure during the day at his prior job. Under the Executive Order, the agency's medical office may not disclose that Richard has a family medical history of this disorder. The agency's medical office may disclose that Richard had a seizure only as permitted by the Rehabilitation Act.[19]

Example D: Sara sought and received health care services from her agency. She voluntarily provided the agency medical office with the results of a genetic test. Several months later, the agency received a subpoena from a court, seeking copies of the protected genetic information that Sara provided. Under the Executive Order, the agency must comply with the subpoena, but first should inform Sara of the demand for the protected genetic information and allow her to contest the subpoena, unless the subpoena imposes a confidentiality requirement.

V. COLLECTION AND USE OF PROTECTED GENETIC INFORMATION

Under the Executive Order, there are limited situations in which Executive departments and agencies may collect and use protected genetic information concerning applicants and employees. The general prohibition and these exceptions are explained in the questions and answers that follow.

7. *May a department or agency request or require **the results of genetic tests** from an applicant, or request or require that the applicant **take a genetic test** under the Executive Order?*

No. A department or agency may **never** request or require the results of genetic tests from an applicant. Nor may a department or agency ever request or require that an applicant take a genetic test.

8. *May a department or agency obtain and use **family medical history** from an **applicant** under the Executive Order?*

Yes, in very limited circumstances. The Executive Order allows department or agency medical personnel to request or require, and to use, **family medical history** from applicants **only if certain conditions are met.**

The **first** condition is that the request or requirement must be "consistent with the Rehabilitation Act and other applicable law."[20] To ensure consistency with the Act, a department or agency may request or require family medical history **only** from **post-offer applicants** - that is, from individuals to whom the department or agency has made conditional offers of employment.[21]

Departments and agencies must meet **three additional conditions** in order to ensure that their **use** of family medical history comports with the Executive Order:

- **only** department or agency medical personnel may obtain family medical history, solely for the purpose of deciding whether further medical evaluation is **needed to diagnose a current disease, or medical condition or disorder**;
- the current disease, or medical condition or disorder must be one that **could prevent the individual from performing the essential functions** of the position for which the individual has been given a conditional offer; **and**
- family medical history may not be **disclosed** to anyone other than **medical personnel** involved in, or responsible for, assessing whether further medical evaluation is needed to diagnose a current disease, medical condition or disorder.[22]

In sum, the Executive Order allows department or agency medical personnel to obtain family medical history from all post-offer applicants in the same job category. The department or agency medical personnel may use family medical history, however, only to help decide whether to conduct further evaluation to diagnose a current disease, medical condition or disorder that could prevent the individual from performing essential job functions.

> *Example A*: An agency makes conditional firefighter job offers to Sergei, Albert, and Cynthia. During a post-offer medical examination, an agency physician asks all three for their family medical histories. Sergei discloses a family medical history of heart disease. Physical limitations associated with different types of heart disease could prevent Sergei from putting out fires or performing certain emergency procedures, which are essential functions of the firefighter job. Based on Sergei's family medical history, the agency may conduct further medical assessment to determine if Sergei currently has a type of heart disease that could prevent him from performing the essential functions of the job.

Example B: Tammi disclosed a family medical history of sickle cell anemia during a post-offer medical examination. She also volunteered information that she participated in a sickle cell screening program. The Executive Order prohibits the agency's physician from requesting information concerning the results of the genetic screening program in which Tammi participated. Under the Executive Order, family medical history is the only protected genetic information to which agency medical personnel are entitled from applicants.

9. *Are the Executive Order's limitations on obtaining and using protected genetic information from applicants the same as the **Rehabilitation Act's restrictions on disability-related inquiries for applicants?***

No. The Executive Order's limitations are **stricter** than those under the Rehabilitation Act, which allows **all** disability-related inquiries of **post-offer** applicants. Under the Executive Order a department or agency is **prohibited** from requesting, requiring, or using **genetic tests** or information from **genetic services** from post-offer applicants, and is limited in the **use** of **family medical history** from such applicants.

10. *May a department or agency require a current employee to **take a genetic test** under the Executive Order?*

No. A department or agency may **never** require that an employee take a genetic test. Nor may a department or agency ever request or require information about genetic tests from an employee.

11. *May a department or agency **obtain and use family medical history** from a current **employee** under the Executive Order?*

Yes, in very limited circumstances. The Executive Order allows department or agency medical personnel to request or require, and to use, **family medical history** from current employees **only if certain conditions are met.**

First, the request or requirement for employee family medical history must comply with the Rehabilitation Act and other applicable law. Whenever department or agency medical personnel could make disability-related inquiries of the employee under the Rehabilitation Act, they may seek family medical history. The Act prohibits employee disability-related inquiries unless they are shown to be "job-related and consistent with business necessity."[(23)] To meet this standard, the department or agency must demonstrate a reasonable belief, based on objective evidence, that:

- the employee's ability to perform essential job functions will be impaired by a medical condition, or
- the employee will pose a direct threat due to a medical condition.[(24)]

Departments and agencies must meet **three additional conditions** in order to ensure that their **use** of family medical history comports with the Executive Order:

- **only** department or agency medical personnel may use family medical history,

solely for the purpose of deciding whether further medical evaluation is **needed to diagnose a current disease, or medical condition or disorder**;
- the current disease, or medical condition or disorder must be one that **could prevent the individual from performing the essential functions** of the position held or desired; **and**
- family medical history may not be **disclosed** to anyone other than **medical personnel** involved in, or responsible for, assessing whether further medical evaluation is needed to diagnose a current disease, medical condition or disorder.(25)

In sum, when a department or agency reasonably believes, based on objective evidence, that an employee's ability to perform essential job functions will be impaired by a medical condition, or that an employee will cause a direct threat based on a medical condition, department or agency medical personnel may request or require family medical history. Family medical history may be used, however, only to determine whether to conduct a further medical evaluation of the employee in pursuit of a diagnosis of a current disease, medical condition or disorder that could prevent the employee from performing essential job functions.(26)

> ***Example A***: An essential function of Delaine's job is moving heavy boxes from a loading dock to a storage area. Delaine's supervisor notices that Delaine has been having problems moving boxes for several days, and that he has been complaining of back discomfort and asking co-workers to move some boxes for him. The supervisor sends Delaine to the agency's health office for an examination.(27) During the examination, Delaine informs the health care provider that he hurt his back lifting a box a week earlier and that he cannot lift the heavier boxes. The health care provider may ask Delaine for his family medical history in order to determine whether a further medical evaluation may be needed to diagnose Delaine's current condition.

The Executive Order also allows a department or agency to obtain family medical history, under limited circumstances, if an employee uses genetic or health care services provided by the department or agency. This exception is discussed in Question 13.

12. *May a department or agency terminate, refuse to hire, or otherwise adversely affect the employment of an individual **based on family medical history**?*

No. Under the Executive Order, family medical history may be used only to decide whether medical evaluation is necessary to diagnose a **current** medical condition that could prevent the individual from performing the essential functions of the position held or desired.

Under the Rehabilitation Act, family medical history, standing alone, can **never** establish that an individual is **not qualified** or poses a **direct threat.** Whether an individual is **qualified** must be assessed based on his/her current ability to perform essential job functions. Whether an individual poses a direct threat must be assessed based on the individual's present ability to safely perform the functions of the job, considering a reasonable medical judgment that relies on the most current medical knowledge and/or the best available objective evidence.(28)

Example A: An agency made a conditional job offer to Alice of a physically demanding and stressful position in a developing country with poor health care facilities. During a post-offer medical examination, Alice disclosed a family medical history of heart disease. Alice does not have heart disease and can perform the essential functions of the job. The agency may not withdraw its conditional job offer based on a fear that Alice may develop heart disease. The decision whether to accept the job is Alice's.(29)

Example B: Alana is a chemist working with toxic and explosive materials on a multi-agency, international project. Scientists from her office routinely are assigned to work overseas with scientists from other countries. Alana is scheduled for assignment to a facility in Asia. She and her supervisor, Jennifer, are friends outside the office and Jennifer knows that several members of Alana's family have died of Huntington's Disease (HD), a degenerative brain disorder for which there is, at present, no effective treatment or cure. Early symptoms include clumsiness, involuntary twitching, and lack of coordination. Alana has not been diagnosed with HD and her current health is excellent. Under the Executive Order, Jennifer could not lawfully refuse to assign Alana to the overseas position because of her family medical history. The decision whether to take the assignment belongs to Alana. In addition, under the Rehabilitation Act, Alana's family medical history would not support the conclusion that she poses a direct threat. (Assuming Alana has told the medical office about her family medical history of HD, department or agency medical personnel may conduct medical evaluations of Alana in the future to diagnose HD, as permitted under the Executive Order and the Rehabilitation Act.)

13. *May a department or agency medical office obtain protected genetic information about an employee who uses **genetic or health care services** that are provided by the department or agency medical office?*

Yes. The Executive Order provides that if an employee voluntarily uses a department's or agency's genetic or health care services, the department or agency medical office may obtain protected genetic information about the employee.(30) A department or agency must meet several conditions as a predicate for obtaining such protected genetic information.

First, the employee must have provided the department or agency with **prior knowing, voluntary, and written authorization** to collect the protected genetic information. Second, such protected genetic information **must not be used to discriminate** against the employee in violation of the Executive Order. Third, the person who performs the genetic or health care services **must not disclose** the protected genetic information, except for the following limited **administrative purposes**:

- to persons assessing the genetic or health care services program;
- to persons verifying that services were provided for payment/accounting purposes (although the genetic information itself may not be disclosed); or
- to persons compiling and analyzing information in anticipation of, or for use in, civil or criminal legal proceedings.

The Executive Order also states that the department or agency may provide the protected genetic information to the employee who has used the genetic health care services.(31)

> ***Example A***: An agency offered its employees free colon cancer screening. During the screening process, agency medical personnel received prior knowing, voluntary, and written authorization from participating employees to obtain protected genetic information, including prior genetic test results and family medical history from the employees' primary health care providers. One of the agency's employees, Corrine, provided both genetic test information and family medical history showing a strong predisposition for colon cancer. Agency medical personnel would violate the Executive Order if they disclosed any of this information except as strictly limited by the exceptions explained in this Guidance. In addition, the agency would violate the Executive Order if it were to adversely affect Corrine's employment based either on her request for health care services or on the specific genetic information disclosed.

14. *May a department or agency get protected genetic information from an **employee** when it conducts **medical research** in which the employee is a **participant**?*

Yes. The Executive Order permits a department or agency to collect protected genetic information about an employee if it complies with the requirements in 45 C.F.R. Part 46, "Protection of Human Subjects." The regulation provides the basic policy of the Department of Health & Human Services concerning the use of human subjects in research.

15. *May a department or agency conduct **genetic monitoring of employees**?*

Yes, under limited circumstances. The Executive Order allows a department or agency to conduct genetic monitoring of the biological effects of toxic substances in the workplace if all of the following conditions are met:

- the department or agency has received the employee's **prior knowing, voluntary, and written authorization;**
- the department or agency notifies the employee when the results are available, makes any protected genetic information that may have been acquired during the monitoring available to the employee, and tells the employee **how to obtain such information;**(32)
- the monitoring **conforms to any genetic monitoring regulations** that may be promulgated by the Department of Labor; and
- the department or agency officials, except for the licensed health care professionals involved in the monitoring program, receive results only in **aggregate terms that do not disclose the identity of specific employees.**(33)

16. *May a department or agency collect protected genetic information for identification purposes?*

Yes. The Executive Order states that a department or agency may collect protected genetic

information as a part of a lawful program, the primary purpose of which is to carry out identification, e.g., to identify human remains.(34)

VI. PROCEDURE FOR ASSERTING NONCOMPLIANCE WITH THE EXECUTIVE ORDER

The Executive Order establishes policy and does not "create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person."(35) Rather, the Executive Order directs the "head of each department or agency [to] take appropriate action to disseminate [the] policy" and identify a high level official to be responsible for "carrying out" the Order's requirements.(36)

If an individual believes that a department or agency has violated the terms of the Executive Order, it would be appropriate for that individual to inform the department or agency official responsible for implementing the Executive Order, regardless of whether the alleged action also may have violated the Rehabilitation Act. Of course, departments or agencies and individuals may always contact the Commission (Office of Legal Counsel) with any questions or concerns about the Executive Order. Doing so will enable the Commission to fulfill its responsibility for coordinating this policy.

VII. ASSERTING VIOLATIONS OF SECTION 501 OF THE REHABILITATION ACT

Applicants and employees in the Executive branch who believe that a department or agency has violated a provision of the Executive Order may be able to pursue a claim under the Rehabilitation Act. To successfully assert coverage under the Rehabilitation Act, applicants and employees first must establish that they meet the definition of an individual with a disability.(37)

17. *Can an individual be **regarded as** having a disability based on information obtained from a **genetic test** or **family medical history**?*

Yes. An employer using information obtained from a genetic test may be "regarding" the individual tested as having an impairment that substantially limits a major life activity. The **"regarded as," or third** prong, of the definition of disability, protects an individual who does not have an **actual disability** (first prong) or a **record of a disability** (second prong). A person who falls solely within the "regarded as" prong of the definition is one:

- who has an impairment that is not substantially limiting but is treated as substantially limiting;
- whose impairment is substantially limiting only because of the attitudes of others; or
- who has no impairment but is treated as having a substantially limiting impairment. (38)

The "regarded as" prong of the definition of disability is intended to **combat the stigmatization** of persons with disabilities as well as discrimination based on the **myths,**

fears, and stereotypes associated with disability.[39] The Supreme Court has noted that generalized "'myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairments.'"[40]

In its Compliance Manual chapter on the definition of the term "disability," the Commission included an example in which an employer withdraws a job offer after learning that the applicant has a genetic profile indicating an increased risk for colon cancer. The employer has concerns about productivity, attendance, and health insurance costs. This employer is treating the individual as substantially limited in a major life activity and the individual is covered under the "regarded as" prong of the definition of disability.[41]

An individual with a **family medical history** of a disease, medical condition or disorder, also may be covered under the "regarded as" prong of the definition of disability. A department or agency that makes an adverse employment decision because of family medical history may be treating an individual with no known impairments as having an impairment that substantially limits a major life activity.

> *Example A*: Jane and her supervisor, Jim, were chatting one day about great baseball players when Jim started talking about Lou Gehrig. Jane mentioned that her father died of "Lou Gehrig's Disease," or amyotrophic lateral sclerosis (ALS), and that her brother recently had been diagnosed with it. When a new slot opened in Jim's unit for a manager, he decided not to select Jane because the job required a lot of training and Jim was deeply concerned that Jane would not work long enough in the job to justify the training. Jim expected Jane would have future absences and limited productivity associated with ALS. Jane is not impaired by ALS, but Jim is regarding her as having an impairment that substantially limits the major life activity of working.[42]

Generalized fears regarding productivity, attendance, safety, liability, accommodation, acceptance by co-workers, and a limited work life may relate to all jobs, and thus may reflect an assumption that the individual is precluded from performing either a class of jobs or broad range of jobs in various classes, and therefore is substantially limited in the major life activity of working.

18. *Can an individual with a misspelled or altered gene associated with a severe disease or disorder [43] be covered under the actual disability prong of the definition of disability under the Rehabilitation Act?*

Yes, in limited circumstances.

An individual with a misspelled or altered gene associated with a severe or fatal disease or disorder may be covered under the actual disability, or first prong of the definition of disability, which protects an individual who has an impairment that substantially limits a major life activity.

Under the Rehabilitation Act, the term "impairment" includes "any physiological

disorder."[44] An alteration or a misspelling in a gene is an "impairment" because it causes cellular and molecular changes leading to disturbances in cell function.

An impairment must substantially limit a major life activity in order to rise to the level of a disability. In *Bragdon v. Abbott*, the Supreme Court held that reproduction is a major life activity.[45] The Court further reasoned that an individual with an impairment that may be transmitted to offspring, and cause a severe or fatal disease or disorder, could be substantially limited in the major life activity of reproduction. Similarly, an individual who has a misspelled or altered gene associated with a severe or fatal disease or disorder, and who could transmit that altered gene to offspring, may have a disability.

> ***Example A***: Fletcher recently tested positive for the genetic alteration that causes Huntington's disease, a degenerative brain disorder. Fletcher currently has no symptoms of the disease. As someone who has the genetic alteration that causes Huntington's, Fletcher has a 50% chance of passing the altered gene to a child. Fletcher would be covered by the first prong of the definition of disability if his impairment, an alteration to the Huntington's gene, substantially limits him in the major life activity of reproduction.

19. *Is an individual who has an **association** with a person who has a disability caused by a genetic impairment protected under the Rehabilitation Act?*

Yes. The Rehabilitation Act prohibits discrimination against an individual based on that person's **association** with an individual with a disability.[46] This provision protects an individual where the individual "is known to have a family, business, social, or other relationship or association" with an individual with a disability.[47] This is true whether the disability is caused by a genetic impairment or another reason.

> ***Example A***: Rosemarie mentions to her supervisor, Antoine, that her aunt has been diagnosed with Alzheimer's Disease and will be coming to live with her because she no longer can care for herself. Antoine decides not to place Rosemarie into a training program because he believes that she will not be available full time for the foreseeable future because of her aunt's illness. Antoine's action violates the Rehabilitation Act because he is discriminating against Rosemarie based on her association with an individual (her aunt) who has a disability.

20. *What is the procedure for alleging a violation of section 501 of the Rehabilitation Act?*

The procedure for bringing an action alleging a violation of section 501 of the Rehabilitation Act is set forth in the Commission's federal sector EEO process regulations.[48] Briefly stated, the federal sector process requires the following:

- the individual alleging discrimination must contact an EEO Counselor within forty-five days of the date of the discriminatory act or within forty-five days of when the individual became aware or should have become aware of the allegedly illegal conduct;
- the department or agency may conduct EEO counseling or offer mediation or other

form of alternative dispute resolution;
- o if the matter is not resolved informally, the agency will give the individual a notice of final interview and the individual will have fifteen days to file a formal complaint;
- o once the formal complaint is filed, the matter will be investigated, and the matter may proceed either to an agency decision or a hearing before a Commission Administrative Judge; and
- o after either the Administrative Judge or the department or agency issues a decision, the matter may be appealed to the EEOC, which will then render a decision.

At various stages of the process, the complainant has the option of filing a complaint in federal court.(49)

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1. Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (2000).

2. The text of President Clinton's remarks at the signing ceremony for the Executive Order may be found at <www.pub.whitehouse.gov/uri-res/I2R?urn:pdi://oma.eop.gov.us/2000/2/8/7.text.2> (visited July 7, 2000).

3. Section 1-103, Exec. Order No. 13,145, 65 Fed. Reg. at 6,877.

4. 29 U.S.C. § 791.

5. Rehabilitation Act Amendments of 1992, Pub. L. No. 102-569, § 503(b), 106 Stat. 4344 (1992) (codified as amended at 29 U.S.C. § 791(g) (1994)). These amendments also apply sections 501-504 and 510 of the ADA to employment discrimination complaints under section 501 of the Rehabilitation Act.

6. Sections 1-102, 1-201(a), 65 Fed. Reg. at 6,877. The term "employee" includes applicants, current employees, and former employees.

7. *Id.* § 1-201(e)(1)(A) - (C), 65 Fed. Reg. at 6,878.

8. *Id.* § 1-201(d). Genes are sections of "DNA" (or "deoxyribonucleic acid") that direct the production of proteins needed for basic cell function. Each gene, in essence, provides the recipe for making a protein within a cell. *See* Matt Ridley, *Genome: The Autobiography of a Species in Twenty-Three Chapters* 12-13 (1999). DNA is a long, coiled, double-stranded chain (called a "double-helix") of chemical base pairs that carry genetic information. *See* Nat'l Cancer Inst., U.S. Dep't of Health and Human Servs., *Understanding Gene Testing* 1-2 (1995) The base pairs are either an A-T or C-G combination; that is, adenine always pairs with thymine and cytosine always combines with guanine. A mutation, or alteration to a gene, is a variation in the "spelling" of a gene that will cause the cell to not work properly. *Id.* at 3-4. The booklet *Understanding Gene Testing*, is available on-line <http://www.accessexcellence.org/AE/AEPC/NIH/index.html> (visited July 13, 2000). Another web-based source of basic genetic information is located at "Geneinfo: Understanding News about Human Genetics," <http://www.geocities.com/geneinfo/index.html> (visited July 13,

2000).

9. Section 1-201(e)(2), Exec. Order No. 13,145, 65 Fed. Reg. at 6,878.

10. *Id.*

11. Disability-related inquiries and medical examinations are permitted under the Rehabilitation Act for post-offer applicants. For employees, inquiries and examinations are permitted if they are job-related and consistent with business necessity. 29 U.S.C. § 12112(d); 29 C.F.R. § 1630.14. The Office of Personnel Management (OPM) also regulates when a department or agency may request or require medical examinations of applicants and employees. *See* 5 U.S.C. § 3301 & 3302; 5 C.F.R. Part 339 (Medical Qualification Determination). OPM regulations note, however, that actions taken under Part 339 must be consistent with the Commission's disability discrimination regulations. *Id.* § 339.103.

12. Section 1-201(b), Exec. Order No. 13,145, 65 Fed. Reg. at 6,877.

13. *Id.* § 1-201(c).

14. *Id.* §§ 1-202(a) - (e), 1-301(a), 65 Fed. Reg. at 6,878-79.

15. *Id.* § 1-202(e), 65 Fed. Reg. at 6,879.

16. 29 C.F.R. § 1630.14(b)(1) & (c)(1).

17. Section 1-202(d)(1) - (4), Exec. Order No. 13,145, 65 Fed. Reg. at 6,878

18. If disclosure is sought in response to a court order or congressional subpoena that was secured without the employee's knowledge, the employee should be given the opportunity to challenge the disclosure before it is made, unless the subpoena or order imposes a confidentiality requirement. *Id.* § 1-202(d)(3).

19. The Rehabilitation Act permits disclosure of medical information, including protected genetic information, under limited exceptions to its confidentiality requirements. These exceptions include:

- supervisors and managers may be told about necessary restrictions on the work or duties of the employee and about necessary accommodations;
- first aid and safety personnel may be told if the disability might require emergency treatment;
- government officials investigating compliance with the Rehabilitation Act must be given relevant information on request;
- employers may give information to state workers' compensation offices, state second injury funds, or workers' compensation insurance carriers in accordance with state workers' compensation laws; and
- employers may use the information for insurance purposes.

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21, 8 FEP Man. (BNA) 405:7191, 7201 (1995). Unions also may have limited access to medical information for reasonable accommodation purposes. *See* EEOC: Opinion Letter on ADA Confidentiality Requirement and Union Rights, 8 FEP Man. (BNA) 405:7527, 7529 (1996).

20. Section 1-301(a)(1), Exec. Order No. 13,145, 65 Fed. Reg. at 6,879. For another applicable regulation, *see, e.g.*, 5 C.F.R. Part 339 (Medical Qualification Determinations).

21. Under the Rehabilitation Act, if a department or agency chooses to condition a job offer on the results of a medical examination, it must ensure that all post-offer applicants in the same job category are subjected to the same examination. 29 C.F.R. § 1630.14(b). A department or agency thus would have to request or require family medical history from all post-offer applicants to the same position.

22. Section 1-301(a)(1) - (4), Exec Order No. 13,145, 65 Fed. Reg. at 6,879.

23. 29 C.F.R. § 1630.14(c) (1999).

24. *See EEOC Enforcement Guidance: The Americans with Disabilities Act and Psychiatric Disabilities* 15, 8 FEP Man. (BNA) 405:7461, 7468-69 (1997).

25. Section 1-301(a)(1) - (4), Exec. Order No. 13,145, 65 Fed. Reg. at 6,879.

26. The Executive Order imposes the same first condition on departments and agencies requesting family medical history from applicants and employees - compliance with the Rehabilitation Act and other applicable law. Because the Rehabilitation Act itself has different standards for applicant and employee disability-related inquiries, the basis for requesting or requiring family medical history differs as between applicants and employees.

27. Sending Delaine to the medical office is permissible under the Rehabilitation Act because the agency has a reasonable belief based on objective evidence that Delaine's ability to perform an essential function of his job is impaired by a medical condition.

28. 29 C.F.R. § 1630.2(r) (1999). For a department or agency to show that an individual poses a direct threat, it must demonstrate that the individual poses a significant risk of substantial harm. 29 C.F.R. app. § 1630.2(r) (1999).

29. If Alice develops heart disease and needs treatment, the department or agency must treat her as it would any other employee who develops a similar need during an overseas posting. If the department or agency as a matter of course, or as required by law or regulation, transports an employee who becomes ill to a location with appropriate health care facilities, it must do the same for Alice, even though she had a family medical history of the illness.

30. *Id.* § 1-301(b), 65 Fed. Reg. at 6,879.

31. *Id.* This section of the Executive Order also allows disclosure for the purposes listed in section 1-202(d), which are noted in this Guidance at Section IV, Prohibitions Under the Executive Order - Disclosure of Protected Genetic Information.

32. The employee must be informed of the process for getting the information the department or agency collects and has the right to decide whether s/he wants the information. An employee's decision not to request the results of the monitoring from his/her employer does not affect the employer's right to engage in monitoring. *Id.* § 1-301(d), 65 Fed. Reg. at 6,879-80.

33. *Id.*

34. *Id.* § 1-301(e)(3), 65 Fed. Reg. at 6,880.

35. *Id.* § 1-403.

36. *Id.* § 1-401.

37. 29 U.S.C. § 12102(2); 29 C.F.R. § 1630.2(g) (1999).

38. 29 C.F.R. § 1630.2(*l*) (1999).

39. *See* H.R. Rep. No. 101-485, pt. 2 at 31-32 (1990).

40. *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 489 (1999) (quoting *School Bd. of Nassau Cty. v. Arline*, 480 U.S. 273, 284 (1987)).

41. EEOC Compliance Manual § 902.8(a), 8 FEP Man. (BNA) 405:7251, 7278-86 (1995).

42. *See generally Heyman v. Queens Village Community*, 198 F.3d 68 (2d Cir. 1999). In reversing summary judgment for the employer, the court noted that a jury reasonably could find that the employer regarded the plaintiff as disabled based on its prior experience with an employee who had the same type of cancer as the plaintiff, who needed time off from work, and who was unable to complete his tasks. The court stated, "A jury could find that defendants' experience . . . led [them] to conclude that [plaintiff], afflicted with the same disease, would likewise be unable to function fully and soon would become a workplace liability." *Id.* at 73. *Cf. Koshinski v. Decatur Foundry, Inc.*, 177 F.3d 599, 603 (7th Cir. 1999) ("It would be hard to imagine . . . that a court would sanction an employer's decision to fire a qualified employee simply because his degenerative heart disease makes a future heart attack inevitable").

43. *See supra* note 8 explaining that a mutation, or an alteration to a gene, is a variation in the "spelling" of a gene that will cause the cell to not work properly. *See* Nat'l Cancer Inst., U.S. Dep't of Health and Human Servs., *Understanding Gene Testing* 3-4 (1995).

44. 29 C.F.R. § 1630.2(h)(1).

45. 524 U.S. 624, 640-41 (1998).

46. *See Polifko v. Office of Personnel Mgmt.*, EEOC Request 05940611 (January 4, 1995);

29 C.F.R. § 1630.8 (1999).

47. *Id.*

48. 29 C.F.R. Part 1614 (1999), as amended by 64 Fed. Reg. 37,644 (1999).

49. A more detailed description of the federal sector equal employment opportunity process and links to the applicable regulations may be found at the Commission's web site, http://www.eeoc.gov (see "Federal Sector Information"). Additional information also is available by calling the EEOC information line at 1-800-669-4000 (TDD 1-800-669-6820).

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ATTACHMENT 4

The U.S. Equal Employment Opportunity Commission

Section 902 Definition of the Term Disability

Section 902 Definition of the Term Disability

This part of the definition of "disability" applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of "disability." See 136 Cong. Rec. H4623 (daily ed. July 12, 1990) (statement of Rep. Owens); id. at H4624-25 (statement of Rep. Edwards); id. at H4627 (statement of Rep. Waxman).

Example -- CP's genetic profile reveals an increased susceptibility to colon cancer. CP is currently asymptomatic and may never in fact develop colon cancer. After making CP a conditional offer of employment, R learns about CP's increased susceptibility to colon cancer. R then withdraws the job offer because of concerns about matters such as CP's productivity, insurance costs, and attendance. R is treating CP as having an impairment that substantially limits a major life activity. Accordingly, CP is covered by the third part of the definition of "disability."

APPENDIX F – SUBMITTED FOR THE RECORD, STATEMENT OF RONALD WEICH, LEGISLATIVE CONSULTANT, AMERICAN CIVIL LIBERTIES UNION, WASHINGTON, D.C.

AMERICAN CIVIL LIBERTIES UNION

WASHINGTON NATIONAL OFFICE
Laura W. Murphy
Director

122 Maryland Avenue, NE Washington, D.C. 20002

(202) 544-1681 Fax (202) 546-0738

Statement of

RONALD WEICH

Legislative Consultant to the American Civil Liberties Union

ON BEHALF OF
THE AMERICAN CIVIL LIBERTIES UNION

for inclusion in the record of the hearing of the
Subcommittee on Employer-Employee Relations
House Committee on Education and the Workforce

on

Genetic Privacy and Non-Discrimination

July 24, 2001

Mr. Chairman and Members of the Subcommittee: My name is Ronald Weich. I am a partner in the Washington D.C. law firm of Zuckerman Spaeder LLP and I serve as a legislative consultant to the American Civil Liberties Union (ACLU). I am pleased to submit for the record of this hearing the views of the ACLU on the subject of genetic privacy and nondiscrimination.

The ACLU is a nationwide, non-partisan organization of nearly 300,000 members dedicated to protecting the principles of liberty, freedom and equality set forth in the Bill of Rights to the United States Constitution. For almost 80 years, the ACLU has sought to strengthen civil rights and civil liberties in all aspects of American life.

We commend the Subcommittee for its attention to the important issue of genetic privacy. Recent scientific advances in understanding and mapping the human genome present opportunities for improved medical care, but also pose challenges to principles of privacy and non-discrimination.

Genetic tests reveal the most intimate and personal health-related information that exists about any individual. While all medical information should be treated as private, genetic information is uniquely sensitive because it may reveal so much about an individual, including the individual's genetic predisposition to medical conditions. Individuals should be allowed to control such quintessentially personal information, and should be empowered by law to shield such information from third parties.

In addition to establishing the privacy of genetic information, federal law should prohibit discrimination in employment or insurance based on genetic information. There are three reasons why Congress should take immediate steps to prohibit the use of such information by employers or insurers:

- First, it is inherently unfair to discriminate against someone based on immutable characteristics that do not affect their ability to perform a job.

- Second, the mere fact that someone has a genetic predisposition to a health condition is an unreliable basis to act on the risk that he or she will actually develop that condition in the future. Genetic tests do not show with certainty that any individual will eventually develop a disease or how severe their symptoms might be.

- Third, the threat of genetic discrimination leads individuals to decline genetic screenings and other health services to avoid revealing information that may be used against them. For example, the Journal of the American Medical Association reports that only 57% of women at risk for breast cancer seek genetic testing, and 84% of those who decline the test do so because they fear genetic discrimination. Dr. Frances Collins and other leading genetic scientists have warned that progress in the field of genetic medicine depends on the willingness of individuals to submit to genetic tests without fear of discrimination.

In recent years a number of states have enacted genetic privacy laws, but the ACLU believes that a comprehensive federal law is needed to ensure that all Americans are protected from this unacceptable form of discrimination. For this reason, the ACLU has endorsed H.R. 602, "The Genetic Nondiscrimination in Health Insurance and Employment Act," introduced by Congresswomen Slaughter and Morella, and cosponsored by over 250 members of the House.

The ACLU supports H.R. 602 because it meaningfully addresses the serious threat

to civil liberties posed by new genetic technology. It prohibits genetic discrimination in all aspects of employment, including hiring and compensation. It prohibits insurers from restricting enrollment or adjusting fees on the basis of genetic information. And it prohibits both insurers and employers from requiring genetic testing.

During the recent debate on the Patients Bill of Rights (S. 1052), the Senate adopted by voice vote an amendment offered by Senator Ensign on the subject of genetic discrimination. There are several reasons why we believe H.R. 602 provides superior protection against genetic discrimination than the Ensign amendment.

The most important respect in which H.R. 602 is preferable is that it bans discrimination by employers as well as health insurers. In contrast, the Ensign amendment only prohibits discrimination by insurers, leaving individuals vulnerable to discrimination in hiring and promotions. Without protections in place in both areas, individuals have reason to fear that their genetic information could be used against them.

Also, the definition of genetic information in the Ensign amendment is narrower than the corresponding definition in H.R. 602. The Slaughter-Morella bill protects information gleaned from all genetic tests, even if the test was not administered for the purpose of obtaining genetic information. In contrast, the Ensign amendment explicitly does not cover information derived from a test administered in order to "detect symptoms, clinical signs, or a diagnosis of disease." Similarly, the Ensign amendment contains an exception that would permit health plans to obtain genetic information "for purposes of diagnosis, treatment or payment" – terms which are not defined in the amendment – while H.R. 602 contains no such exception.

Finally, H.R. 602 grants individuals a more complete judicial remedy than the Ensign amendment. Unlike H.R. 602, the Ensign amendment requires individuals to rely on overworked government agencies to vindicate their rights, at least initially, and limits the penalties levied on violators.

It has been suggested by some that H.R. 602 may be unnecessary because the Americans with Disabilities Act ("ADA") already prohibits employment discrimination based on genetic information. We agree that Congress intended the ADA to prohibit genetic discrimination. Unfortunately a series of court decisions, notably Sutton v. United Airlines, Inc., 527 U.S. 471 (1999), has narrowly defined the term "disability" under 42 U.S.C. § 12102 (2) and has thereby limited the scope of ADA protections. Individuals who are symptomatic but not disabled can no longer rely on the protection of the ADA, and individuals with a genetic predisposition to an illness that has not yet manifested itself are also likely to fall outside the ADA's protected class.

While we continue to believe that the ADA should be read to prohibit genetic discrimination, we believe it is entirely appropriate for Congress to clarify its intent to outlaw this pernicious practice. At this critical juncture, new legislation is needed to eliminate any ambiguity regarding protections for this most personal of information.

Indeed, whether in the course of this genetic non-discrimination bill or as a separate initiative, Congress should strengthen the ADA by overturning Sutton and similar cases that interpret the Act too narrowly. Congress should make clear that unwarranted discrimination against anyone on the basis of disability is impermissible, whether the victim of discrimination is: (1) actually disabled; (2) symptomatic but not disabled; or (3) genetically predisposed to a disability or medical condition but not symptomatic. Enactment of a genetic non-discrimination law would be welcome in that it

would extend civil rights protection to non-symptomatic individuals, but such a law would inadvertently create a gap in federal law in which discrimination against individuals in the middle category (symptomatic but not disabled) will still be permissible.

In sum, the ACLU believes that Americans should be judged on their actual abilities, not their potential disabilities. No American should lose a job or an insurance policy based on his or her genetic predisposition. We urge Congress to adopt H.R. 602, the Genetic Nondiscrimination in Health Insurance and Employment Act, and to take such other steps as may be necessary to ensure the privacy of genetic information.

APPENDIX G – SUBMITTED FOR THE RECORD, STATEMENT OF LPA, WASHINGTON, D.C.

STATEMENT

OF

LPA

CONCERNING
H.R. 602, THE GENETIC NONDISCRIMINATION IN HEALTH INSURANCE AND EMPLOYMENT

BEFORE THE SUBCOMMITTEE ON
EMPLOYER-EMPLOYEE RELATIONS

HOUSE COMMITTEE ON EDUCATION AND THE WORKFORCE

WASHINGTON, DC

JULY 24, 2001
(01-125)

1015 FIFTEENTH STREET | SUITE 1200
WASHINGTON DC 20005
202.789.8670 | FAX 202.789.0064 | WWW.LPA.ORG

Dear Mr. Chairman and Members of the Committee:

Thank you for this opportunity to present the views of LPA regarding the Genetic Nondiscrimination in Health Insurance and Employment Act (H.R. 602).

As you may know, LPA is a public policy advocacy organization representing senior human resource executives of over 200 leading employers doing business in the United States. LPA provides in-depth information, analysis, and opinion regarding current situations and emerging trends in labor and employment policy among its member companies, policy makers, and the general public. Collectively, LPA members employ over 19 million people worldwide and over 12 percent of the U.S. private sector workforce. LPA member companies have revenue exceeding $4.3 trillion annually.

LPA has several concerns with H.R. 602. First, while the practice of discrimination on the basis of genetic information is indefensible, no compelling need for the legislation has been demonstrated. Second, the bill establishes new procedures and remedies for discrimination claims that are not consistent with those established for employment discrimination claims arising under Title VII or the Americans with Disabilities Act. Third, the bill's definition of genetic discrimination is too broad and could impose liability for unsolicited information. Finally, LPA is concerned that the bill's prohibition on employer-provided genetic services does not provide adequate exceptions to preserve employer wellness programs.

Our overriding concern is that the enactment of sweeping new legislation in this area will simply open the door for more litigation at a time when the economy and the judicial system are already overburdened with an explosion of employment actions. While any new enactment is likely to contribute further to this problem, we agree with President Bush that, if legislation is to be enacted, it should be "fair, reasonable, and consistent with existing discrimination statutes."

The Need for a New Federal Ban Against Genetic Discrimination Has Not Been Established

Although there is currently no specific prohibition against genetic discrimination under any federal law, it has been claimed that at least two statutes—the Americans with Disabilities Act (ADA) and Title VII of the Civil Rights Act—potentially provide protection against such genetic discrimination. The fact that such protection under these laws is largely untested in the courts is likely a reflection of the absence of any significant incidence of genetic discrimination by employers.

Americans with Disabilities Act (ADA). The ADA was enacted in 1990 to protect against discrimination in employment on the basis of disability and to provide equal access to public accommodations to persons with disabilities. Although the law does not specifically address genetic discrimination, the EEOC has taken the position, in its 1995 Guidance on Disability,[1] that genetic discrimination is prohibited under the definition of "disability" that protects individuals who are "regarded as" having impairments that substantially limit one or more major life activities.[2] Thus, an individual with no actual impairment (or no record of an impairment) may still be deemed to be "disabled" under the ADA if other persons perceive or regard that individual as having an impairment that would substantially limit a major life activity. This prong of the ADA is designed to protect against unfounded myths, fears, and stereotypes about individuals with disabilities

and reflects Congress' determination that the reaction of others to an impairment or a perceived impairment should be prohibited the same way as discrimination based on an actual impairment.

In addition, the ADA provides protections to employees who are asked to undergo medical examinations. The ADA contains specific provisions dealing with the ability of employers to request or obtain medical information or to require medical examinations. For example, the ADA prohibits any medical inquiries or medical examinations at the pre-offer stage of the employment application process.[3] Genetic testing constitutes such a medical inquiry or examination; thus, under the ADA, an employer is prohibited from requiring all job applicants to undergo genetic screening.

It has been contended that a case decided by the U.S. Supreme Court in 1998 affords some support for the position that the ADA provides protection against genetic discrimination. In *Bragdon v. Abbott*,[4] an individual infected with the HIV virus who had not yet exhibited any of the symptoms of AIDS was ruled to be disabled. The Supreme Court reasoned that a physical impairment existed, based on virus-related changes that occurred at the cellular and molecular levels after infection, even if these changes were not yet externally visible to others. Although it is not yet clear how other courts would apply this case to a claim of genetic discrimination, it has been argued that it provides support for ADA protection of the presence of genetic markers for a currently asymptomatic genetic disorder.

In addition to providing employees with protections against the improper use of genetic discrimination, the ADA may also provide a defense where an employer can demonstrate a nondiscriminatory reason for considering an employee's genetic information. For example, the employer may seek 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. In such situations, the ADA recognizes that an employer may impose the qualification standard that an employee not pose a "direct threat" to the health or safety of others in the workplace,[5] and the EEOC has expanded this statutory definition to include threats to the individual with the disability.[6]

Title VII of the Civil Rights Act. While there is no case law to confirm this, it could be contended that Title VII, which protects members of a protected class, may serve to prohibit genetic discrimination against a member of an ethnic or racial group where certain diseases have been found to be more prevalent (*e.g.*, sickle cell anemia in individuals of African descent or Tay-Sachs disease in Ashkenazi Jews). Thus, were an employer to use genetic information regarding a disease that is highly correlated with the race, ethnicity, national origin, or gender of an employee in order to discriminate against such a class, a court could possibly find a violation of Title VII.

The existence of these potential protections under current law casts serious doubt upon the urgency for enactment of a new scheme of genetic discrimination protection. Indeed, the very fact that existing protections are untested reflects an absence of litigation, further suggesting minimal incidence of discrimination.

The Broad Prohibition in H.R. 602 Fails to Protect Employers with Inadvertent Access to Employee Genetic Information

H.R. 602 defines the term "protected genetic information" as information about an individual's genetic tests (or those of a member of his or her family) or information about the occurrence of a disease or disorder in family members. This definition is so broad that it not only includes information derived from genetic tests, but also any information about the occurrence of a disease or disorder in family members. One major concern of employers is that the bill provides no defense for employers who inadvertently receive genetic information, for example, in routine health insurance claims, or who receive unsolicited information concerning family histories. If such information came to an employer's attention, under the bill's prohibition against the collection of genetic information, the employer would be exposed to potential liability for compensatory and punitive damages in federal court.

In addition, upon the filing of a genetic discrimination claim, the burden would be on the employer to convince a jury that the employer's knowledge of such information—even where obtained without solicitation—was not a factor in any adverse employment action taken after receipt of the information. This burden may be so great as to force employers to settle many of these cases rather than risk taking them to an uncertain jury.

The Remedies and Procedures Available Under H.R. 602 Are Inconsistent with Those of Existing Federal Discrimination Laws

Rather than treating genetic discrimination the same as other forms of discrimination, H.R. 602 ignores procedural and remedial components that have been built into other federal discrimination laws to guard against frivolous and excessive litigation. The bill's sponsors have failed to establish a justification for this inconsistency, despite the absence of current empirical evidence of widespread abuse of genetic information. The fact is that employers do not routinely require genetic testing or collect genetic information about their employees or base employment decisions on such information.

Unlimited Damages. An individual who prevails under the bill may receive *unlimited* compensatory damages—such as future pecuniary losses, emotional pain, suffering, inconvenience, mental anguish, loss of enjoyment of life, and other nonpecuniary losses—and punitive damages for violations (see chart). In contrast, compensatory damages under Title VII and the ADA may not exceed the statutory cap based on the number of people employed by the employer. For employers of more than 500 employees, the maximum amount of compensatory and punitive damages provided by both Title VII and the ADA is $300,000.[7] The reason why Congress chose to adopt this limit in the Civil Rights Act of 1991 was to seek to avoid the proliferation of litigation that has occurred under other laws where unlimited compensatory and punitive damages, which can be highly speculative and disproportionate, are available. Even with the statutory cap, there has been an explosion of litigation since the 1991 enactment adding compensatory and punitive damages to federal discrimination actions. In fact, the number of discrimination lawsuits filed annually tripled after the 1991 amendments. As Justice O'Connor has noted, the value of any increase in the availability of monetary relief must be evaluated by weighing the likely increase in deterrent effect against the additional incentive for unmeritorious litigation.[8] Statistics show that the addition of

limited damages under the 1991 amendments failed this test. The unlimited damages proposed in H.R. 602 will only serve to enhance that mistake.

Even if the Congress believes legislation should be passed to explicitly prohibit employment-based genetic discrimination, the remedies available to plaintiffs should be consistent with those available under other discrimination laws.

Comparison of Damages Available Under H.R. 602, Title VII, and the ADA

	H.R. 602	Title VII	ADA
Combined Compensatory and Punitive Damages	Unlimited	14-100 employees: capped at $50,000 101-200 employees: capped at $100,000 201-500 employees: capped at $200,000 > 500 employees: capped at $300,000	14-100 employees: capped at $50,000 101-200 employees: capped at $100,000 201-500 employees: capped at $200,000 > 500 employees: capped at $300,000
Back Pay	Unlimited	Unlimited	Unlimited
Front Pay	Unlimited	Unlimited	Unlimited

Absence of Procedural Safeguards. H.R. 602 is also inconsistent with existing discrimination laws in its enforcement scheme. An individual pursuing a claim under the bill may file suit directly in federal court, with no statute of limitations specified. In contrast, individuals pursuing claims under either Title VII or the ADA must first file a charge of discrimination with the EEOC or the authorized state or local agency.[9] Moreover, the complainant has a limited time in which to file a complaint following the alleged discriminatory action. Where there is no authorized state or local agency, such a charge must be filed with EEOC within 180 days of the alleged discriminatory act. In states or localities where there is an authorized state or local agency, a charge must be presented to that state or local agency, and the complainant must file charges with the EEOC within 300 days of the discriminatory act or 30 days after receiving notice that the state or local agency has terminated its processing of the charge, whichever is earlier. The EEOC (or authorized state or local agency) then investigates the charge. If the evidence obtained in an investigation does not establish that the alleged discrimination occurred, this will be explained to the complainant. A required notice is then issued, closing the case and giving the complainant 90 days in which to file a lawsuit on his or her own behalf. This administrative process helps screen out frivolous claims and promotes the timely resolution of all claims.

Because the bill lacks the administrative procedures accorded other discrimination claims, including a time limitation for the filing of an action, there is no way to screen out frivolous charges before they clog our already overburdened federal courts. There is no compelling reason why genetic discrimination, unlike other forms of prohibited discrimination, such as discrimination based on race or sex, should not be subject to the

EEOC's procedures of testing the sufficiency of the complaining employee's charges prior to litigation or why these claimants should be entitled to punitive and compensatory damages greater than those available to most other claimants of employment discrimination.

H.R. 602 Poses a Threat to Corporate Wellness Programs

While the bill does permit employers to provide "genetic services" should individual employees consent, the bill could still threaten employer-sponsored wellness programs. This is because the bill requires that genetic information only be received by the employee or a family member of the employee.

Due to increased costs of providing health benefits and costs related to employee illness, many companies have decided to establish wellness programs with the goal of creating a healthier workforce that will, in turn, decrease insurance and other health-related costs on the company. A typical program would provide employees with individual health risk assessments and then pinpoint strengths and weaknesses and provide information on how the employee can lower health risks. While health data is treated as confidential and not used in employment decisions, companies do use information for statistical purposes, such as identifying how health costs are affected based on employees with various risk factors participating in the program. Consequently, by offering wellness programs, employers could be exposed to liability under this bill.

Conclusion

Mr. Chairman and members of the committee, the Genetic Non-discrimination in Health Insurance and Employment Act, with unlimited liability for compensatory and punitive damages and the lack of any screening process for frivolous claims, has the potential to foster new litigation within our already overcrowded judicial system and generate new, unwarranted workplace disputes. The case for legislation is further weakened by the absence of any compelling evidence that significant numbers of employers are engaging in genetic discrimination or that existing laws are inadequate to protect employees. LPA urges you to consider these matters as the committee considers this legislation.

Thank you again for this opportunity to testify today.

Endnotes

[1] EEOC Compliance Manual (BNA) 902.8(a) (1995).
[2] 42 U.S.C. § 12102(2)(C).
[3] 42 U.S.C. § 12112(d)(2)(A).
[4] 524 U.S. 624 (1998).
[5] 42 U.S.C. § 12113(3).
[6] 29 C.F.R. § 1630.2(r). However, in *Echazabel v. Chevron USA, Inc.*, 226 F.3d 1063 (9th Cir. 2000), the Court of Appeals for the Ninth Circuit refused to apply the direct threat standard to the health or safety of the individual. Chevron USA Inc. is seeking U.S. Supreme Court review of the decision. Recently, the Supreme Court invited the solicitor general to express the view of the Bush administration on the scope of the direct threat defense available to employers under the ADA. *Chevron USA Inc. v. Echazabal*, U.S., No. 00-1406, interim order (June 18, 2001).
[7] 42 U.S.C. § 1981a(b)(3). The cap on damages under Title VII and the ADA, however, does not include damages for front pay. Recently, the U.S. Supreme Court unanimously ruled in *Pollard v. E.I. du Pont de Nemours & Co.*, U.S. No. 00-763 (June 4, 2001), that front pay awards in cases under Title VII are not an element of compensatory damages and, thus, not subject to the damages caps. The damages provisions under the ADA are identical to those under Title VII; thus, the Court's ruling is likely applicable to that statute as well. *See* 42 U.S.C. § 12117(a); 42 U.S.C. § 1981a(a)(2).
[8] Smith v. Wade, 461 U.S. 30, 93-94 (O'Connor, J. dissenting).
[9] Many states and localities have antidiscrimination laws and agencies responsible for enforcing those laws. The EEOC refers to these agencies as fair employment practices agencies (FEPAs). Through the use of work-sharing agreements, EEOC and the FEPAs avoid duplication of effort.

APPENDIX H – SUBMITTED FOR THE RECORD, LETTER TO CHAIRMAN JOHN BOEHNER, COMMITTEE ON EDUCATION AND THE WORKFORCE, FROM JEFFREY MORELAND, EXECUTIVE VICE PRESIDENT LAW AND CHIEF OF STAFF, BURLINGTON NORTHERN AND SANTA FE RAILWAY COMPANY (BNSF), FORT WORTH, TX, MAY 7, 2001

BNSF

JEFFREY K. MORELAND
Executive Vice President Law and Chief of Staff

Corporation
P. O. Box 961052
Fort Worth TX 76161-0052
2650 Lou Menk Drive
Fort Worth TX 76131-2830
817-352-1350
817-352-7111 Fax
jeffrey.moreland@bnsf.com

May 7, 2001

The Honorable John A. Boehner
Chairman
Education and the Workforce Committee
U.S. House of Representatives
1011 Longworth House Office Building
Washington, DC 20515-3508

Dear Mr. Chairman:

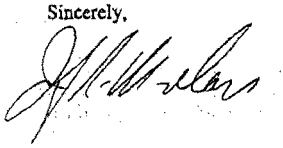
This letter expresses the support of The Burlington Northern and Santa Fe Railway Company (BNSF) for the establishment of national standards governing the use of genetic testing by employers.

BNSF wholeheartedly supports the passage of Federal legislation prohibiting employment discrimination on the basis of genetic testing or genetic information. We have reviewed the major companion bills that have been introduced in Congress on the subject (S.318 and H.R. 602) and would offer the following comments.

The purpose and objectives of these bills are laudable and both deserve support. We are unable to comment on Title I of these bills since we do not have the expertise to recommend changes to these insurance-related provisions. On the other hand, as an employer, BNSF endorses the thrust of Section 202 of Title II to the extent it prohibits employers from discriminating in employment decisions on the basis of "protected genetic information".

BNSF will continue to find ways to make known its support of national standards for governing the use of genetic testing that prohibits employment discrimination.

Sincerely,



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