



TESTIMONY OF

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**HEARING ON
“PROTECTING AGAINST GENETIC DISCRIMINATION:
THE LIMITS OF EXISTING LAWS”**

**SENATE COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS**

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Testimony of Debra L. Ness, National Partnership for Women & Families
Senate Committee on Health, Education, Labor, and Pensions
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Good morning Mr. Chairman and Members of the Committee. My name is Debra Ness and I am grateful for the opportunity to testify today on behalf of the National Partnership for Women & Families on some of the legal issues related to genetic discrimination.

The National Partnership for Women & Families is a nonprofit, nonpartisan organization, dedicated to improving the lives of women and families. Through public education and advocacy, the National Partnership promotes fairness in the workplace, quality health care, and policies that help women and men meet the dual demands of work and family. The National Partnership works with government, business, advocates, unions, and the media to make the concerns of women and families our nation's priorities.

The National Partnership has been a leader on the issue of genetic discrimination for years, because women have been at the center of so many advances in genetic research. From the earliest pre-natal testing, to more recent and sophisticated breast and ovarian cancer screening, women have had and will continue to have a great deal at stake in the genetics revolution. Women know first-hand the difficult balance between the benefits of genetic testing and the potential economic and emotional harm that knowledge of a potential birth defect or predisposition to illness can bring. We also know that women are the primary decision-makers about health care in most families, and thus it is women who are already helping their parents, siblings, or children make these difficult decisions.

The National Partnership founded and leads the Coalition for Genetic Fairness, made up of patient groups, civil rights and civil liberties groups, women's groups, people with disabilities or potential disabilities, and health care providers. The coalition is urging Congress to pass comprehensive, clear federal protections against genetic discrimination in employment and insurance. The Coalition for Genetic Fairness has developed the following core principles that we believe must be met in legislation banning genetic discrimination.

Coverage/Definitions: Legislation must cover all genetic information -- including family history -- that predicts future health risks in healthy individuals.

Scope: Legislation must prohibit both health insurers and employers from collecting predictive genetic information and from using it to discriminate in the health care system and the workplace.

Strong Enforcement: Legislation must provide individuals who experience genetic discrimination the right to seek redress through legal action, with access to meaningful remedies.

Privacy/Disclosure: Legislation must ensure that those entities holding genetic information about individuals will not disclose it to third parties without the permission of the individual.

No individual should have to choose between the benefits of genetic testing and keeping a job or health insurance. In some cases, fear of genetic discrimination can be as destructive as actual discrimination. Already we know that many people use false names or pay for expensive tests out-of-pocket, in an attempt to avoid being identified with the results of their tests. Others forgo testing altogether. We believe that unless Congress acts quickly and decisively, people's fears about genetic discrimination may prevent them from getting the health care they need. And the more individuals fear discrimination, the less willing they will be to participate in clinical trials and studies that may require genetic testing – the very kind of research that could help all of us live longer, healthier lives.

It is important to note that genetic tests are not perfect indicators of whether an individual will develop a particular disease. Rather, most of the tests currently available reveal an increased likelihood that a disease will manifest itself. This can be crucial, life-saving information for an individual who may pursue preventive measures and treatment as a result of knowing his or her own risks.

Scientists predict that within 20 years we will each be able to go to the doctor and have our own genetic predispositions thoroughly tested, in order to know exactly what our increased risks are. Every one of us has predispositions to a variety of conditions -- scientists estimate somewhere between 5 and 50 -- and knowing our genetic makeup will allow us to reduce our risks through preventive medicine or lifestyle changes. It is important to emphasize that none of us will leave the doctor's office with a "clean" genetic profile – all of us, right now, are carrying these predispositions. That is why genetic discrimination legislation is so critical to every man, woman, and child in this country.

I have been asked to testify today because of our legal expertise in the area of genetic discrimination, and to respond to questions about whether current law is adequate to prevent genetic discrimination.

The need for both health and employment protections

We need clear, strong protections from genetic discrimination in both health insurance and employment. Passing legislation that only addresses genetic discrimination in health insurance without addressing employment discrimination, or vice-versa, is a glass that is much less than half full. The fear of losing one's job is about

more than loss of employment. Most Americans who have private health insurance receive that insurance through their job or a family member's job. This link between employment and health insurance increases Americans' concern that employer know more than they should about employees' private medical information and will use that information inappropriately to make decisions about hiring, firing, training and promotions. It is compounded by the fear of losing health coverage for themselves and their families, and potentially never being able to find employment and health coverage again. Without protections in place against genetic discrimination in both employment and health insurance, individuals and their families are left vulnerable to significant harm.

Some lawmakers believe that current law, specifically the Health Insurance Portability and Accountability Act (HIPAA) and the Americans with Disabilities Act (ADA), or state laws, already provide sufficient protection from genetic discrimination. We disagree.

The Inadequacy of Protections in HIPAA

The National Partnership played a key role in helping to pass HIPAA, and in particular, the inclusion of a provision that prohibits genetic discrimination in group health insurance. HIPAA solved one important, but small piece of the puzzle. HIPAA guarantees that individuals who are in a group health plan cannot be denied insurance or have their individual rates raised because of their genetic information. But HIPAA leaves many gaps unfilled.

HIPAA only provides limited protections to people in the group market. It does not protect people in the individual market from being denied coverage or being charged unaffordable premiums because of their genetic information. In the group market, HIPAA does not prevent plans from charging more to all members of a group plan because of the genetic makeup of specific members of the group. Indeed, HIPAA would not prevent a health plan from making a group's health insurance premiums so high that coverage became unaffordable, effectively denying health coverage to the entire group. And, for large groups, HIPAA does not prevent a health plan from deny coverage to a group outright because of one or a few members' genetic information. In the real world, these gaps mean that although an individual in a group plan could not be denied insurance, an entire office or company could lose health insurance because of the genetic information of one individual.

In recent testimony before a subcommittee of the House Energy and Commerce Committee, the Health Insurers Association of America (HIAA) relied on a report by the American Academy of Actuaries to assert that insurers do not now use predictive genetic information in underwriting. ("Genetic Information and Medical Expense Insurance," American Academy of Actuaries, June 2000) If this is true, we think the industry should have no objection to a federal law that prohibits such practices. Indeed, the report states "Family history is rarely, if ever, used in evaluating applicants for individual medical expense insurance because it has not proven to be a good predictor of short-term medical

costs.”

However, the report also states that insurers in the individual market *do* ask for the results of any prior genetic testing, and that that information “may or may not prevent the individual from being able to purchase individual medical expense insurance at a standard premium.”

What all of this means is that the insurance industry has been inconsistent in its views of how, or even whether, to fill the gaps left by HIPAA. On the one hand they say they don’t want and won’t use genetic information. On the other hand, they oppose legislation that would prevent them from obtaining and using genetic discrimination in underwriting. What is clear, however, is that HIPAA is inadequate, and leaves gaping holes, which could allow insurance companies to use genetic information in a discriminatory way.

The Inadequacy of the Americans with Disabilities Act

When the Americans with Disabilities Act passed, many hoped that it would provide protection from genetic discrimination. Indeed, the EEOC issued guidelines for employers stating that the ADA protects employees from genetic information. However, this interpretation of the ADA has never been fully tested in the courts, and because of recent federal court decisions weakening the ADA’s scope of coverage generally, we are uncomfortable relying on that theory as the sole legal protection from genetic discrimination in employment.

As the testimony of Andy Imparato indicates, it would be difficult for a plaintiff to win a genetic discrimination lawsuit under the ADA. Although Congress included language in the ADA to protect people “regarded as” disabled, the courts have interpreted this “regarded as” prong very narrowly. In addition, although the Supreme Court held in Bragdon v. Abbott that an asymptomatic HIV positive individual was protected by the ADA because she was substantially limited in the life activity of reproduction, it is unclear whether the Court’s reasoning in Bragdon gives meaningful protections to an asymptomatic individual with a genetic predisposition to a disease. Because of the uncertainty of the protection from ADA, Congress must enact specific legislation addressing the issue of genetic discrimination and must also address the many ways the ADA itself has been weakened.

The Inadequacy of State Laws

Although many states have begun to address the issue of genetic discrimination in state laws, they vary greatly and often do not go far enough. Many do not cover both insurance and employment discrimination. Some have narrow definitions of what genetic information is protected, some excluding family history from the definition of what information is protected. Some laws address genetic information related to only specific diseases, such as cancer. Others appear to have good protections but have no enforcement mechanisms, rendering them ineffective. Even if the patchwork of

protections in the state were more complete, we believe a uniform federal law is necessary to provide a strong federal floor of protections. An individual's civil rights should not depend on where he or she lives.

Why the National Partnership for Women & Families endorses S. 318/H.R. 602

Based on the principles developed by the Coalition for Genetic Fairness and based on the inadequacy of current law, the National Partnership for Women & Families strongly endorses S. 318, the Genetic Nondiscrimination in Health Insurance and Employment Act sponsored by Senators Tom Daschle (D-SD), Christopher Dodd (D-CT), Ted Kennedy, (D-MA), and Tom Harkin (D-IA). An identical House bill is sponsored by Representatives Louise Slaughter (D-NY) and Connie Morella (R-MD). The bill would provide the protections Americans need from genetic discrimination in health insurance and in the workplace.

S. 318 is much stronger than other legislative proposals, such as S. 382 introduced by Senator Snowe or the amendment offered by Senator Ensign during the debate on the Patients' Bill of Rights, in several ways. Unlike other proposals, it includes protections from discrimination in employment. Without such protections, individuals could lose their job, *and their employment-based health insurance*, on the basis of genetic information. People will continue to fear genetic discrimination unless such comprehensive protections are in place.

S. 318 also more comprehensively defines what genetic information is protected from misuse. It protects all predictive genetic information, while other legislative proposals have remarkably narrow definitions of what genetic information is protected. S. 382 for example, exempts information from protection if it is "derived from physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests." Since virtually all genetic information is collected by "chemical, blood, or urine analyses," this definition essentially it guts the entire notion of a bill outlawing genetic discrimination, by excluding all genetic information from protection.

S. 382 also leaves unprotected any information that was discovered through a test not intended to reveal genetic information – for example, a routine cholesterol test that reveals information linked to a genetic predisposition to disease. We believe that all predictive genetic information should be protected, and not subject to arbitrary exceptions based on the intent of the test that revealed it.

Finally, S. 318 provides meaningful remedies for those who are victims of genetic information, whereas S. 382 does not. We believe that all plaintiffs must have the opportunity to be fully compensated for the wrong done to them. Artificial caps on damages in effect protect the worst offenders by protecting them from full liability. In addition, we believe that an employee's ability to seek strong penalties acts as an important deterrent against illegal behavior by employers and insurers.

Some have suggested that in the employment context, caps on damages similar to

those in Title VII or the ADA would be appropriate. The National Partnership for Women & Families has always opposed caps on damages, we opposed them in the context of Title VII and the ADA, and we believe that such caps do significant harm to plaintiffs seeking meaningful relief under civil rights laws. Capping damages means an employer knows exactly how much that discrimination will cost, and can act purely out of economic self-interest if the amount at stake seems worth the price. Uncapped damages deliver the strongest possible incentive against discrimination. In addition, in the context of health insurance discrimination, we strongly believe that even if the protections offered by HIPAA were more complete, the remedies available to individuals for violations of HIPAA currently are very limited, and the penalties that could be imposed on an employer amount to no more than \$100 per day.

Without the ability to enforce the rights, discrimination protections will be of little use. Indeed, the availability of significant monetary penalties and damages against violators has a deterrent effect, and will be a strong incentive for employers and insurers to comply with the law.

The need for genetic discrimination legislation is real and immediate

Let me conclude by directly addressing the objection to genetic discrimination legislation that we hear most often – the notion that this is not a real problem, that employers and insurers do not want and would not use this information to discriminate against individuals. That is false. In July, this Committee heard from one of the workers in the Burlington Northern Railroad case, where Burlington Northern has admitted they were using genetic testing to determine if workers who had developed Carpal Tunnel Syndrome had a predisposition to the disease.

I want to tell you about another case that you haven't heard about yet. Several months ago my office was contacted by a woman whom I'll call Mary, although that is not her real name. Mary is in her early thirties, and because of her extensive family history of very early deaths from breast cancer, she underwent genetic testing to determine if she has the BRCA1 and BRCA2 genetic predisposition to breast cancer. Unfortunately, the test revealed that she does have this genetic predisposition, which combined with her family history, indicates that she is at high risk of developing breast cancer

After months of discussion with her doctors, Mary decided to undergo a prophylactic mastectomy. Even though she has no signs of the disease now, her doctors determined this to be the best preventive treatment for her to be able to maintain a long, healthy, and productive life. In Mary's case, her small office knew about her testing and the reason for her decision to undergo preventive surgery. But a few weeks later Mary was notified that she was being fired, despite excellent reviews and recent promises of promotions and raises. It was clear that the information about her genetic testing had come back to haunt her.

Mary will, of course, try to seek a fair resolution to her situation under the limited protections in current federal and state law. However, for all the reasons I have discussed, Mary deserves clear protections from genetic discrimination in health insurance and employment that she and all of us can rely on. I urge Congress to act quickly to pass S. 318.