

About the Coalition for Genetic Fairness

The **Coalition for Genetic Fairness** is an alliance of civil rights, patients' and health care organizations created to urge Congress to pass comprehensive federal legislation outlawing genetic discrimination. Current federal and state laws do not provide the protections needed to prevent employers and insurers from denying health coverage or job opportunities on the basis of genetic information. The Coalition was founded by several national organizations and today represents thousands of Americans working together to promote strong federal protections against genetic discrimination.

Coalition for Genetic Fairness

In Care of the National Partnership for Women & Families
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About the National Partnership for Women & Families

The **National Partnership for Women & Families** is a nonprofit, nonpartisan organization that uses public education and advocacy to promote fairness in the workplace, access to quality health care and policies that help women and men meet the dual demands of work and family. The National Partnership's Health Care Program helps women navigate the changing health care system and works to ensure access to quality, affordable health care.

Founded in 1971 as the Women's Legal Defense Fund, the National Partnership has grown from a small group of volunteers into one of the nation's most powerful and effective advocates for women and families. Working with business, government, unions, nonprofit organizations, and the media, the National Partnership is a voice for fairness, a source for solutions, and a force for change.

The National Partnership is particularly concerned about the issue of genetic discrimination. There are now genetic tests for more than 500 disorders, and many of the most widely available tests are for women. Although the discovery of genetic markers for breast and ovarian cancer should be good news for women's health, the underlying threat of genetic discrimination has meant that many women are fearful of undergoing testing. Women and their families need comprehensive, enforceable limits on who has access to genetic information and how it can be used. Through its work as a founding and leading member of the Coalition for Genetic Fairness, the National Partnership supports the enactment of strong federal protections against genetic discrimination in health insurance and employment.

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ACKNOWLEDGMENTS

This report, *Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People*, could not have been completed without the hard work and assistance of many individuals. Staff at the National Partnership for Women & Families devoted countless hours and much energy to conceptualizing, researching, writing, editing, and producing this report. The principal authors were Debra L. Ness, Alice M. Weiss, Myra Clark-Siegel, and law clerk Courtney A. Rogers. Substantial contributions in collecting, organizing, and reviewing submissions for this report were made by Vanessa Lopes, Ali Cherry, and our consultant Andrea Maresca of DDB Bass & Howes. In addition, Debbie Wilkes, Kamilah Woods, and our communications intern Trista Kendall provided invaluable assistance in formatting and editing the document. We are also deeply indebted to the dedicated commitment of our consultants, Joanne Howes of DDB Bass & Howes and Lisa Lederer and Gretchen Wright of PR Solutions, for their excellent input and clear thinking which helped to shape and strengthen the final report.

This report would not have been possible without the valuable and informative contributions made by members of the Coalition for Genetic Fairness and others, and their contributions are acknowledged specifically in this report. In addition to these contributions, a number of organizations and individuals provided invaluable data, reports, research, and advice that improved the document significantly. In that regard, the National Partnership would like to thank staff at the National Institutes of Health National Human Genome Research Institute, and Kathy Hudson, Susannah Baruch, and Daryl Pritchard at the Johns' Hopkins University Genetics and Public Policy Center.

***Faces of Genetic Discrimination:
How Discrimination Affects Real People***

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Introduction

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 traditional discrimination. Unless Congress acts quickly and decisively, people's fears 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.¹

***- Debra L. Ness, President
National Partnership for Women & Families***

In an era filled with technological and scientific marvels, one of the most significant scientific accomplishments has been cracking the human genetic code – a breakthrough that is already transforming the battle against a broad range of medical conditions. After a nearly \$3 billion investment,² society is finally beginning to reap the benefits of this new technology.

Scientists have already identified genetic markers for various diseases and health conditions, including cancer, diabetes, Alzheimer's disease, Huntington's disease, cystic fibrosis, and potentially thousands of others.³ Genetic tests are currently available to identify predispositions to specific conditions,⁴ and more are expected as science advances.⁵ Although none of these tests predict with full certainty that a condition will develop, they provide a new opportunity for individuals to know more about the potential risk of disease for themselves and their families. Once informed about their genetic status, individuals can take proactive steps to protect their health, enhance their well-being, and lower health care costs for themselves and society as a whole.

However, the enormous promise of genetic research and technology is not being realized. Along with the increasing prevalence of genetic testing comes a growing fear that employers and health insurance companies will use genetic information to deny access to employment or health insurance coverage. Numerous respected surveys report that the vast majority of Americans want to keep their genetic information private. The more individuals know about genetic technology and their own risk for a genetically linked condition, the more likely they are to report concerns that employers or insurers will misuse their information. Discrimination based on genetic information is especially pernicious because genetic markers nearly always only indicate an increased chance, but no certainty, that a manifested condition will develop.

Although some state and federal laws now protect against genetic discrimination in health insurance and employment, these laws are limited and incomplete, leaving individuals vulnerable once their genetic information is known. People who fear they will lose their job or health insurance because of their genetic makeup avoid getting tested, never realizing the potential benefits of early detection and prevention. They also shy away from participating in medical research, hindering scientific progress and the ability to fully enter this new era of medical promise. As a result, individuals and our society as a whole cannot enjoy the full benefits and savings that could be reaped from genetic science.

Public concern about genetic discrimination will only increase as genetic science advances and becomes a greater part of our medical care. A few policymakers confronted with these concerns allege that discrimination is not prevalent and therefore is unworthy of attention. But genetic discrimination and the fears about its effects are real and are already having a major impact on our health care system. There is a human cost to genetic discrimination that is too often hidden from public view. This report reveals the faces of those affected by genetic discrimination in America today.

*Genetic discrimination is unfair to workers and their families. It is unjustified – among other reasons, because it involves little more than medical speculation. A genetic predisposition toward cancer or heart disease does not mean the condition will develop. To deny employment or insurance to a healthy person based only on a predisposition violates our country’s belief in equal treatment and individual merit.*⁶

- President George W. Bush

*The potential for medical advances made possible from our knowledge of the human genome are dramatic. Research involving the human genome may open doors to new methods of medical diagnoses and treatment - to a new practice of medicine involving drugs designed for specific genes, genetically engineered organs for use in transplants, or even the ability for preventive care based in large part on genetic testing. At the same time, we must ensure that this information is not used to harm people. We must protect consumers from the threat that their genetic information may be used to deny them access to health insurance coverage or to the benefits of employment. This is a moral responsibility and a practical necessity. [The Senate genetic nondiscrimination] legislation takes that necessary step by protecting individuals with genetic predisposition toward certain diseases from the threat of discrimination.*⁷

**- Senator Bill Frist, M.D., Majority Leader
U.S. Senate**

*Almost two centuries ago, Thomas Jefferson, one of this country’s foremost scientists and original thinkers, wrote that ‘laws and institutions must go hand in hand with the progress of the human mind. As...new discoveries are made [and] new truths disclosed...institutions must advance also, and keep pace with the times.’ In this age of genetic breakthroughs, it is essential that our laws catch up with the science. We can’t afford to take one step forward in science but two steps backward in civil rights. Our laws must specify, clearly and unambiguously, how genetic information may be used and how it may not be used.*⁸

**- Senator Thomas A. Daschle, Minority Leader
U.S. Senate**

*Sometimes, the human face of issues can get lost in Congress amid the general debate. The reality behind this issue is that without prompt legislative action, people will suffer. Average Americans are already being subject to genetic discrimination, and their ranks will grow. Some people will be denied treatment altogether and go without if they cannot afford it. Others will receive treatment but not be able to pay, thereby contributing to the skyrocketing cost of health care in our nation and the growing burden of medical costs on our federal, state, and local governments. Still others will manage to scrape together enough to purchase treatment, but will suffer terrible financial hardship in the process. This is a tragedy we can prevent. This is a tragedy we must prevent.*⁹

**- Congresswoman Louise McIntosh Slaughter
U.S. House of Representatives**

Faces of Discrimination

Genetic discrimination is occurring today in two primary areas: health insurance and employment. Several well-documented cases of health insurers' and employers' attempts to use an individual's genetic information against them have already been reported. Some health insurers have denied coverage to healthy individuals based on their genetic profile. Insurers have also used genetic information in the medical underwriting process, either to increase the price of coverage or to limit coverage for related benefits.

Employers have used genetic information to deny employment, fire current employees, or deny workers compensation benefits. A 2001 American Management Association survey of U.S. firms found a number of employers already accessing genetic information in a number of ways – one percent was conducting genetic tests for Sickle Cell Anemia, 0.4 percent was testing for Huntington's disease, 14 percent were conducting workplace susceptibility testing which surveyors acknowledged might include genetic testing, and 20 percent were requesting family medical histories.¹⁰ Employers' increasing access to genetic information poses new threats of employers misusing this information in their employment decisions, fueling Americans' fears that they may be at risk.

It is impossible to say how many thousands of Americans are affected by this problem today. Many who experience discrimination may be afraid, uncomfortable, or unable to come forward with their story. Others steer clear of discrimination by avoiding genetic services altogether. Those who fight discriminatory practices and win often have to invest significant time, money and effort to assert their rights. Unfortunately, not every victim will have the savvy and resources available to mount such a defense. Most are simply without meaningful protections against discrimination. Many will find themselves uninsured or unemployed at considerable personal and financial risk because of their genetic makeup. Here are some of the faces of those already affected by discrimination in health insurance and employment.¹¹

Health Insurance Discrimination

*Having a gene associated with Alzheimer's disease does not mean a person has the disease. The presence of a gene is not a basis for underwriting insurance premiums for health care...nor should it be used to infringe on any individual's access to care and services.*¹²

- Alzheimer's Association

Jacob

Jacob, a boy who carries a gene for a disorder called Long QT Syndrome (LQTS), was denied coverage under his father's health insurance policy because of his "pre-existing condition." LQTS is a rare and little-known genetic disorder that sometimes triggers sudden cardiac death. Those who carry the gene may be healthy until they suffer an attack without warning, but carriers can control their risk of cardiac arrest with preventive beta-blocker therapy. Jacob's father wanted Jacob to be insured, but even after their state enacted a law prohibiting genetic discrimination, Jacob's insurance company still refused to cover him. After fighting the insurance company for a year and a half, Jacob's family finally won and got Jacob the health insurance he needed.¹³

Heidi

Heidi was denied health insurance for her children, who were carriers of Alpha-1-Antitrypsin Deficiency, a genetic condition that destroys lung tissue and exposes those with the disease to emphysema and difficulty breathing. Even though medical professionals knew that Heidi's children would never develop the disease themselves, the insurance company nonetheless denied them coverage because they carried the Alpha-1 genetic marker. Heidi appealed the decision a number of times, but her appeals were denied. Her insurance company only finally reversed its decision after a reporter contacted the insurer indicating that Heidi's story was to be profiled in a national newspaper.¹⁴

Anonymous

A 28-year-old woman who tested positive for BRCA-1, one of the genes that indicates a predisposition to breast cancer, was denied health insurance coverage because of her genetic status. Although she was not asked for genetic information when she applied for insurance, when the woman reported on her application that she had undergone prophylactic mastectomies and a hysterectomy, the insurance company requested her medical records, which included her genetic information. Her application for coverage was rejected and she was later able to determine that the denial was due to her positive BRCA-1 test result. Only after involving a lawyer, and after much time and effort, was she ultimately able to secure insurance coverage.¹⁵

Employment Discrimination

Workers fear that employers will use genetic information to lower their insurance and sick leave costs by weeding out individuals who have traits linked to inherited medical conditions. There is both hard and anecdotal information indicating that employees' fears are not baseless, and that the problem will only get worse as technology develops.¹⁶

**- Commissioner Paul Miller
U.S. Equal Employment Opportunity Commission**

Gary Avary

Gary Avary's employer, Burlington Northern Santa Fe Railroad, tried to fire him after he refused to undergo mandatory genetic tests. Gary was diagnosed with Carpal Tunnel Syndrome (CTS) in 2000 and took leave from work to have surgery and recover. When he returned to work, Gary was told that he would have to undergo a mandatory medical examination. Gary was told that if he refused to submit to the examination he would be fired. He later learned that his employer was administering secret genetic tests to workers without their consent to identify a possible genetic predisposition to CTS as a defense to workers' compensation claims. Gary refused to take the exam and his employer began disciplinary proceedings to fire him. After seeking help from his union and the Equal Employment Opportunity Commission (EEOC), who filed and settled a suit against Burlington Northern on Gary's behalf, Gary was finally reinstated.

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 – your employer, insurance companies or anyone else has no business of that knowledge. That information.... should not be used against you and your family for hiring and firing practices, or acceptance and/or denial into insurance programs.¹⁷

**- Gary Avary, Worker
Burlington Northern Santa Fe Railroad**

Kim

Kim was a social worker with a human services agency until she was fired because of her employer's fears about her family history of Huntington's disease. During a staff workshop on caring for people with chronic illnesses, Kim mentioned that she had been the primary caretaker for her mother, who died of Huntington's disease. Because of her family history, Kim had a 50 percent chance of developing the disease herself. One week later, despite outstanding performance reviews, Kim was fired from her job.¹⁸

One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up.... [T]he conditions tested for were aspects of one's health in which one enjoys the highest expectations of privacy.¹⁹

**- Judge Stephen Reinhardt
U.S. Court of Appeals, Ninth Circuit**

Berkeley Labs

Between 1968 and 1993, Lawrence-Berkeley Laboratories, a state and federal research institution, gave its employees pre-placement and annual medical examinations that included tests for syphilis, sickle cell genetic markers and pregnancy that were given without the employees' knowledge or consent. This testing was revealed and condemned in a major lawsuit decided in 1998, in which the court held that the employers' actions constituted the "most basic violation possible" of the employees' rights to privacy guaranteed under the Constitution.

As the cost of testing declines and the number of conditions with identified genetic links increases, genetic testing and the use of genetic information may become as common in the American workplace as drug testing is today. In the absence of meaningful legal protection, we may well be on the road to a future in which thousands, or even millions, of people face lifelong job discrimination –and worse – because of something over which they have no control and which has no bearing on their ability to perform their jobs. This is not only a massive injustice, it denies society the benefit of the contributions they could have made in their productive years.²⁰

**- Jeremy Gruber, Legal Director
National Workrights Institute**

Fear of Discrimination

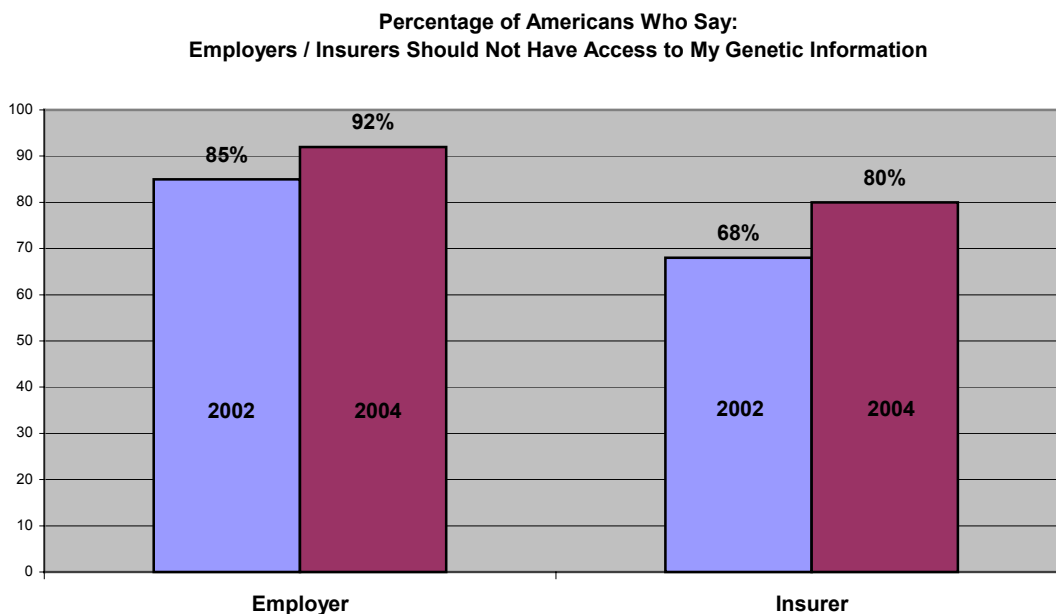
We are on the verge of a true revolution in medicine. But there is a chance it will not happen as we hope. It will not be a failure of the science. There is increasing evidence people fear their genetic information will be used to deny them health insurance or a job. This fear is keeping them from seeking medical help. If people believe that a new system of individualized medicine will lead to denial of health insurance or other benefits, they will not take advantage of what the new system could offer. The revolution at hand may not be realized because people are afraid to take part in it.²¹

**- Dr. J. Craig Venter, President and Chief
Scientific Officer
Celera Genomics**

The fear that health insurers and employers will misuse genetic information is real and exacts a human cost. Numerous respected studies indicate that a strong majority of Americans do not want insurers or employers to have their genetic information, and that they are increasingly concerned about the risk of genetic discrimination.

- A 2004 survey by the Genetics and Public Policy Center at Johns Hopkins University found that an overwhelming majority of Americans do not want their employers or health insurers to have access to their genetic information. Over 9 out of 10 individuals (92%) oppose allowing employers access to their genetic information, and 8 out of 10 (80%) oppose allowing health insurers access. Among college-educated respondents, nearly all (97%) oppose both employer and insurer access.²²

Americans' Growing Concerns about Access to Genetic Information



Source: JHU Genetics & Public Policy Center Survey "Public Awareness and Attitude about Genetic Technologies" (2002, 2004)

- In a 2001 academic survey, more than eight in ten Americans (84%) expressed concerns that health insurance companies would deny coverage based on genetic information. Nearly seven out of ten (69%) believed that employers would deny jobs because of genetic testing results.²³
- A 1998 study by the National Center for Genome Resources found that more than eight out of ten individuals (85%) surveyed did not want employers to have access to information regarding employees' genetic conditions, risks, or predispositions.²⁴
- Americans' concern about misuse of genetic information is longstanding – nearly a decade ago, a 1995 Harris Poll reported that most Americans were worried that their genetic information could fall into the wrong hands – among the general public, 86 percent of those surveyed were concerned that employers and insurers might have access to, and use, genetic information.²⁵

Research also shows that the fear of discrimination can prevent individuals at risk from getting tested or participating in clinical research that could save their lives.

- In a 2003 study of 470 people with a family history of colorectal cancer who enrolled in the Hereditary Colorectal Cancer Registry at The Johns Hopkins Hospital, nearly half rated their level of concern about genetic discrimination as high. Those individuals with high levels of concern indicated that they would be significantly less likely to consider meeting with a health care professional to discuss genetic testing, or to undergo testing. If they were to pursue testing, the individuals who had a higher level of concern reported they would be significantly more likely to pay out-of-pocket, use an alias, or ask for results to be excluded from their medical record.²⁶
- A 2000 survey of 296 cancer genetics specialists' views about what they would do if they were personally at 50 percent or greater risk for carrying a BRCA mutation, found that nearly seven out of ten of the specialists (68%) said they would not bill their insurance companies for genetic testing because of fear of genetic discrimination.²⁷
- In a 1997 survey by the National Center for Genome Resources, 63 percent of participants reported that they would not take genetic tests for disease if employers and health insurers could access the results.²⁸

The real stories of individuals struggling with the choice of whether or not to get tested illustrate the considerable impact that fear of genetic discrimination is currently having on Americans' health care decisions and attitudes.

Mary

Mary had a family history of breast cancer – both her mother and an aunt had been diagnosed with the disease. Concerned about her own future, Mary considered being tested for BRCA-1, hoping to take prophylactic measures to reduce her risk if the result was positive. Ultimately, she decided not to take the test because she feared a positive result would jeopardize her chances for promotion at her law firm.²⁹

*It was extremely important to me to know that I could be tested and not dropped from my insurance or job if I were found out to have a BRCA1 or BRCA2 mutation.... The fear of possibly having a disease and either losing insurance or a job when I would need it most, would be frightening beyond words. How sad if people like myself, who are most at risk, would not test and therefore possibly die an early and preventable death.*³⁰

- Anonymous

Anonymous

A patient advocate working at an oncology clinic had a telling encounter with a young woman whose mother and sister died of breast cancer. The young woman visited the clinic, but refused to sign in. The advocate explained that registration was required, and that the woman's genetic information would be kept entirely confidential. The woman became extremely emotional, saying that she believed she would expose herself and her children to the risk of discrimination if her visit were in any way documented. The advocate tried to encourage the woman to stay, but she left the office without testing or counseling, and without scheduling a screening.³¹

*Despite the availability of insurance reimbursement for genetic testing, many patients still choose to pay cash in advance of genetic testing and only submit to their insurance company if their test is negative. Such a course of action is not available to individuals who are not able to afford this option. A major reason for patient cancellation in our clinic is advice from a physician or friend not to be tested because of fear of discrimination.... Such a fear stands as a barrier to improved and targeted preventive care and screening.*³²

- American Society of Clinical Oncology

Costs to Individuals

The risk of genetic discrimination takes a toll on individual health and financial well-being. Perhaps the most critical benefit genetic testing offers is its potential to improve personal health by enabling individuals to better predict risk and possibly to prevent or delay the onset of serious health conditions. A predictive test for diabetes risk, for example, could influence an individual to make dietary and lifestyle changes that might significantly improve his health prognosis, lessening, delaying or even preventing the onset of disease altogether.³³ If a woman has a BRCA-1 genetic mutation, a bilateral prophylactic mastectomy can reduce her risk of developing breast cancer by a striking 90 percent.³⁵ As more tests are developed, increasing numbers of people will be able to reap dramatic health benefits from genetic tests. Conversely, foregoing genetic tests due to a fear of discrimination means a loss of opportunity to improve one's health.

Unfortunately, many individuals do not seek genetic services because they fear genetic discrimination. This fear hampers the medical care of individuals and their families, either because it prevents them from obtaining beneficial medical information or because individuals who undergo genetic testing decide not to share these results with their health care providers.³⁶

- National Society of Genetic Counselors

Individuals' fear of discrimination often leads them to shield their genetic information, even from their health care providers, but this can actually pose new health risks. When people refuse to be tested, or are tested using an alias or other device which keeps the results out of their medical records, they lose the benefit of more complete medical histories which could have enabled their health providers to better diagnose, treat, or prevent the onset of illness. Doctors are not fully informed, which can hinder patients' ability to get the best care possible and ultimately jeopardize their health.

Gail

Gail, a physician with a family history of breast and ovarian cancers, faced potentially disastrous consequences because of her incomplete medical records. Gail decided to take a genetic test to determine her risk for cancer. In order to avoid losing health insurance coverage, she took the test under an assumed name and kept her family history information out of her medical record. Before she received her results, Gail's gynecologist noticed a possible abnormality on her ultrasound during a routine visit. As Gail's risk factors for cancer and her genetic test were not noted on her medical chart, her doctor was unaware of a possible hereditary risk, and recommended neither follow-up testing nor a course of treatment. Thankfully, as a physician Gail understood the significance of her exam results and knew what she needed to do to protect herself. For most other patients, however, this story could have had a different ending, with the lost opportunity for follow-up resulting in a missed detection of a life-threatening disease.³⁷

Fear of genetic discrimination can also have an adverse financial impact. The early detection and prevention that genetic tests can offer could lessen the financial costs caused by untreated or undetected illnesses, but those who fear discrimination will avoid these tests and consequently may face thousands of dollars in additional health care costs. Individuals treated at a later stage

of illness often face the double whammy of health problems compounded by financial crisis – significant cost-sharing and out-of-pocket medical bills that can threaten mounting medical debt. Medical debt is a leading source of personal financial bankruptcy in our nation, and can lead to home foreclosures and financial ruin for an entire family. The burden of lost income during extended illness can also be crippling. Individuals who can access and use their genetic information without fear will be at lesser risk for these financial losses.

Individuals who fear future discrimination may face an additional financial strain if they choose to pay for their genetic tests out-of-pocket to keep the information out of their medical record. For those who can afford this option, there are significant costs – genetic testing and counseling can cost thousands of dollars for a single diagnosis.³⁸ Unfortunately, many cannot afford the expense of testing, and their fear of genetic discrimination ultimately prevents them from reaping the health and financial benefits of knowing their own genetic information.

Janet

Janet is a cancer survivor with a family history of breast and ovarian cancer and a sister who tested positive for BRCA-1. Janet wanted to be tested for the BRCA-1 gene in order to help her son and his future children make informed health care decisions. She was prepared to pay the \$325 required for the test, an amount she was told the test would cost based on the availability of her sister's results. But when the lab lost her sister's results, the cost of Janet's genetic test jumped to \$3,000. She was covered under her husband's health insurance, but wanted to pay for the test out-of-pocket to avoid discrimination. Since she could not afford the \$3,000, she chose not to be tested. She now fears she will never know her genetic risk.³⁹

Costs to Families

[Taking a genetic test] would help me make some personal choices in my life like whether or not I should have more children. Since my sister died my life has been on hold. I can't go forward unless I know whether or not I carry this gene. If I can, I hope to avoid what happened to my sister from happening to my loved ones or me. The current laws just don't offer enough protection. I can't risk losing my job, paying higher health premiums, or being denied future coverage. Neither can my family.⁴⁰

- Julie, Patient

Genetic discrimination puts entire families at risk. Unlike most other medical tests and diagnoses, an adverse genetic test can have a substantial impact both, for the individual who is tested, but also for their entire family tree. Even if one family member is willing to take the risk of discrimination to get tested, she cannot escape the impact that a positive result could have on her family. In the genetic age, medical information and decision-making have ripple effects for all blood relations – when a patient gets a genetic test, her results could have an impact on access to insurance or employment for her mother, her son, her sister, her grandson. And, because many individuals are covered under family health insurance policies, even non-blood family members are affected by insurers' decisions to deny coverage or limit benefits based on genetic information.

Julie

Julie has a long history of breast and other cancers in her family. Tragically, her sister discovered that she was sick with breast cancer while pregnant with her third child and died only a little over a month after giving birth. After a string of similar tragedies, Julie consulted a genetic counselor, and learned that there was a strong chance that a gene was responsible for these family deaths. But Julie and many members of her family remain afraid to undergo testing.

Kathy

Kathy is a breast cancer survivor with a strong family history of the disease. Her daughter initially encouraged Kathy to get tested for the BRCA-1 gene. After the testing, however, her daughter changed her position completely, based upon her own fear of genetic discrimination. Kathy's daughter now refuses to be tested herself or to participate in any genetic research.⁴¹

Becky and Kate

Becky is a breast cancer survivor whose 20-year-old daughter, Kate, has tested positive for the BRCA-1 gene. Kate, still in college, already faces tough choices about her future health insurance and employment. Kate needs to keep group health insurance coverage - if she loses coverage, she puts herself at risk for having to shop for coverage in the individual market, where insurers can reject her outright or charge her exorbitant rates due to her genetic status. Kate also knows that carrying the BRCA-1 gene means she needs access to quality, affordable health coverage more than most young women her age. Becky devotes her energy to this issue out of concern for her children.⁴²

Impact on Public Health

Unfortunately, while there are over 1 million Americans that carry genetic mutations which dramatically increase their risk of developing cancer, fewer than one percent know it.... Ultimately, this reduces quality of care and wastes healthcare dollars in the treatment of otherwise preventable or, at least, manageable conditions.⁴³

**- Gregory C. Critchfield, President
Myriad Genetic Laboratories**

Genetic discrimination also has an impact on public health. Millions of people could benefit individually from knowing their genetic profile, adding up to fewer seriously ill patients overall, which could ease the stress on our already overburdened health care system. However, the risk of discrimination has kept millions of Americans from taking advantage of these preventive services that could deter illness, improve health outcomes, and reduce costs system-wide. Delayed preventive and therapeutic treatment can lead to higher health care costs in the form of higher out-of-pocket costs and health insurance premiums for the insured, and a greater need for uncompensated care for the uninsured or underinsured.⁴⁴ This increases the financial and physical burden on health care providers,⁴⁵ drives up health care costs for employers, and strains public health resources.⁴⁶ Insurers' ability to limit or deny coverage based on genetic information also leads to greater numbers of uninsured and underinsured individuals, which reduces access to needed health care services and increases costs for the entire health care system.

Individual choices to forego genetic tests because of fear also rob our nation of the potential public health benefit of increased awareness of rare genetic disorders. If people with rare genetic markers are afraid to come forward, their stories cannot be heard. But by sharing what they have experienced and learned, they can raise awareness, campaign for funding and research, and help others to understand confusing symptoms and diagnoses, thereby improving public health outcomes.

[My family] decided that what we had learned from [our experience with Long QT Syndrome] needed to be shared beyond the confines of our family. If this could happen to us, we wondered, how many others had lost a child under similar circumstances and did not have a clue as to the cause?⁴⁷

**- Doris Toran Goldman, Co-Founder and Director
Cardiac Arrhythmias Research & Education
Foundation (CARE)**

Racial and Ethnic Discrimination

*Genetic information may be linked to certain ethnic and racial groups, many of whom have suffered from discrimination and eugenic policies that historically were “justified” by genetic findings. For example, restrictive immigration laws against Eastern Europeans in the 1920s, sterilization policies, Nazi atrocities, and insurance and employment discrimination against carriers of the sickle cell trait were justified by the power of genetic information. Even the discovery in the mid-90s of specific gene mutations that may be associated with higher rates of breast and ovarian cancer in the Ashkenazi Jewish community has raised concerns about how this information may be used to discriminate against them. The African American and Indian communities are also very concerned about behavioral genetic studies on violence and alcoholism.*⁴⁸

- Karen H. Rothenberg, Dean, Marjorie Cook Professor of Law, and Founding Director of Law and Health Care Program, University of Maryland School of Law

Scientists have found several genetic markers that seem to be more prevalent in certain races and ethnicities. For example, women of Ashkenazi Jewish descent are more likely to have the BRCA-1 mutation that indicates a predisposition toward breast cancer.⁴⁹ African Americans are more likely to carry the gene for sickle cell disease.⁵⁰ For certain minority groups, public perceptions about genetic status could compound existing societal racial and ethnic discrimination.

A dramatic and telling example of the ways in which genetic discrimination could compound existing racism occurred in the early 1970s with a scientific mandate to use genetic tests to screen for sickle cell anemia and its impact on the African American community. At that time, scientists had raised concerns that individuals with sickle cell anemia carried a heightened risk from some workplace toxins. Screening programs were developed to identify both healthy carriers and carriers with a manifested condition. Although African Americans were not the only ethnic group at risk for being genetic carriers for sickle cell anemia, states that instituted mandatory genetic screening targeted only this community. They did not mandate screening for other groups, despite the fact that other ethnicities, such as individuals of Mediterranean descent, might also be at risk to carry the disease.⁵¹ Results were not kept confidential, and individuals identified as carriers were stigmatized and discriminated against in employment and health insurance.

Fortunately, Congress passed the National Sickle Cell Anemia Control Act in 1972, barring states from receiving federal funds unless their sickle cell screening programs are voluntary. However, for African Americans, the history of genetic discrimination and its reinforcement of institutional racism resonate more intensely. And their experience provides a telling lesson for all of us about the potential for invidious discrimination that could arise from new discoveries in genetic technology.

*Imprecise press accounts and other forms of misinformation have raised the specter that Jewish women have a unique and greatly heightened predisposition to breast cancer, with implications for potential discrimination in employment and insurance.*⁵²

- Hadassah, The Women’s Zionist Organization of America

Impact on Scientific Advancement

[Genetic discrimination] can slow the pace of scientific discovery that will yield crucial medical advances... Without protections in place, individuals who do participate will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find better ways of diagnosing, treating and preventing disease... The longer this problem remains unresolved, the greater the damage that will be done to U.S. science and medicine.⁵³

**- James D. Watson, President
Cold Spring Harbor Laboratory, and
Dr. Francis S. Collins, Director
National Human Genome Research Institute
National Institutes of Health**

Fear of genetic discrimination has also kept many individuals from participating in medical research studies, stunting scientific advancement and undermining the tremendous investment in new technologies that the federal government and private industry have already made. Genetic research holds tremendous promise to unlock new diagnoses and new treatments, and even to assist in the tailoring of pharmaceutical therapies for an individual's genetic makeup. However, scientific research and development cannot progress without clinical trials, and these trials can only move forward if individuals who could benefit are willing to participate. Fear that information will be made public, or will become available to health insurers or employers, has chilled participation in many studies of genetic conditions. Low participation rates in already developed genetic tests may also chill further private investment in developing new tests. Because of the fear of discrimination, science cannot fully realize the advances and benefits that await on the horizon.

Understanding the function of genes in key biological processes will also become an even bigger part of drug discovery and development. This information could, for example, tell us how and why certain diseases afflict certain people and why certain medications are safe and effective for some people, but not others with the same diagnosis. Thus, genomic information could speed the development of cures and treatments for illnesses that afflict millions of Americans and their families. However, public fear and anxiety are obstacles to achieving this goal.⁵⁴

**- Carl B. Feldbaum, President
Biotechnology Industry Organization (BIO)**

[Federal] legislation will provide protection to those generous individuals considering participating in clinical studies and clinical trials. I am afraid that without it, it will be extremely difficult or impossible to carry out the large clinical studies needed in many important disease areas.⁵⁵

**- Janet A. Warrington, PhD, Vice President for
Clinical and Applied Genomic Research &
Development
Affymetrix, Inc.**

Need for Strong Federal Protections

This is an exciting and hopeful time for genetic medicine. It is imperative, however, that we, the public, can take full advantage of new medical advances that could help prevent disease before it develops. Genetic nondiscrimination legislation will reduce the likelihood of genetic information being misused in health insurance or employment decision-making.⁵⁶

**- Sharon F. Terry, President/CEO
Genetic Alliance**

Current state and federal laws provide a limited patchwork of protection against genetic discrimination whose gaps leave Americans vulnerable. A majority of states have enacted protections against genetic discrimination in health insurance or employment or both, but these laws are inconsistent and limited in what and who they cover. These state laws fail to ensure a uniform floor of protections in employment and health insurance on which American families can rely. And in the health insurance context, they fail to ensure coverage for a sizable number of those covered by private health insurance coverage. Because of a federal law known as the Employee Retirement Income Security Act of 1974 (ERISA), many of these state laws may not apply to as many as 131 million American workers and families covered under private, job-based health plans.

State laws certainly have had a limited impact. Almost no one knows they exist, they are not enforced and, to my knowledge, no cases have been tried using them. But the hundreds of individuals who have self-reported experiences of genetic discrimination still require relief.⁵⁷

**- Paul Billings, PhD., Board Member
Working Group on Genetic Discrimination & Privacy
Council for Responsible Genetics**

Federal law provides some protections, but they are also limited and incomplete. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) established some protections for individuals in group health plans, namely that they cannot be rejected for coverage or charged more than others in the group based on their genetic information. However, HIPAA still allows insurers to charge an entire employer group more for coverage because of one individual's genetic information, which can deter employers from hiring or keeping individuals they suspect may have a genetic predisposition to disease. HIPAA also offers no nondiscrimination protections to individuals purchasing coverage in the individual market, and few states extend these protections to individuals. The federal HIPAA privacy rules also create some protections to ensure the privacy of genetic information, as with all medical information, but they are not strong enough to provide security against insurers either collecting or disclosing private genetic information.

In the employment context, civil rights protections under the Americans with Disabilities Act (ADA) purport to protect individuals against genetic discrimination by employers who perceive genetic predisposition to disease as a form of disability. However, these protections are untested and uncertain. Although the Equal Employment Opportunity Commission (EEOC) has brought at least one suit to enforce these rights in the Burlington Northern case discussed above, that case was settled and it is unclear how a court would rule on the EEOC's interpretation of the law.

Proving employer bias under the ADA has also been a difficult burden for employees to meet, and recent decisions by the Supreme Court that limit the reach of the ADA and narrow its protections indicate that it is not likely to provide a wellspring of support for employees seeking to enforce new rights.

For Americans at risk for genetic discrimination, these gaps in the law pose a serious barrier to their security. Without strong, meaningful federal protections, genetic discrimination will continue to be a serious problem that has a real and human cost for Americans, as individuals and as a nation.

It's a very important point to state that it will be much easier to nip this in the bud before it has become widespread than to wait until there is already a sort of standard practice in the insurance industry or the human resources office to find out information about people's genetics. That's one of the reasons I think it's very shortsighted to say: 'We don't have strong evidence of a lot of trouble now, so let's just wait.' The longer you wait, the harder it will be to fix this problem.⁵⁸

**- Dr. Francis S. Collins, Director
National Human Genome Research Institute
National Institutes of Health**

Conclusion

Our nation is at a crossroads. We can realize the enormous promise of genetic research by ensuring that Americans do not lose their health insurance or their jobs because of their genetic test results. Or we can allow a patchwork of inadequate and incomplete protections to continue, forcing millions of people to choose between their economic security and the genetic tests that can improve their health and possibly prolong their lives.

One thing is clear. Lawmakers have a critical decision to make. Without strong, meaningful federal protections, genetic discrimination will continue to be a serious problem that has a real cost for Americans – and there will be many more faces of genetic discrimination in the months and years ahead. The well-being of our nation is at stake.

Appendix: More Faces of Support for Genetic Nondiscrimination Legislation

A broad and diverse array of organizations is joining in support of federal genetic nondiscrimination legislation. Here are a few examples of these organizations and their rationale as to why this remains a critical national priority.

American Civil Liberties Union:

Individuals need clear and comprehensive protections against genetic discrimination in the workplace and in the provision of health insurance. The current patchwork of state and federal law does not provide needed basic protection against genetic discrimination. Congress must protect employees from employers or insurance companies who have the opportunity to discriminate based on genetic characteristics. The House should pick up the baton handed to it by the Senate by passing genetic privacy legislation to protect the health and livelihood of all Americans.⁵⁹

Alpha-1 Foundation and Alpha-1 Association:

As a genetic condition, those with Alpha-1 or seeking Alpha-1 testing may face health, employment, or insurance discrimination, [the fear of] which may significantly impact individual and family decision-making... [E]arly diagnosis and treatment improves health outcomes and allows the individual to make lifestyle and therapeutic changes that can slow the progression of this devastating lung disease and delay the need for transplantation. The Alpha-1 Coded Testing Trial has offered individuals an opportunity to receive confidential test results since September of 2001; since 2001 2,400 test kits have been requested. [Of t]hose returning the test kits and responding to [a] survey questionnaire, [o]ver 30% report fear of losing insurance as the reason for seeking confidential testing [and] 34% report concern about facing higher health care costs if results were public.

American Academy of Pediatrics:

[T]he American Academy of Pediatrics is concerned that genetic discrimination is a barrier for families to access health insurance for their children. More than 9 million children are currently uninsured in this country, and millions more are underinsured. We will never achieve our goal of ensuring that every child has health insurance coverage if genetic discrimination is permitted. The American Academy of Pediatrics therefore urges Congress to pass legislation that protects American families from genetic discrimination.⁶⁰

American Cancer Society:

Genetic research is one of the most exciting areas of scientific advancement today. As our knowledge about the genetic basis of common disorders grows, however, so does the potential for discrimination in health insurance and employment. This possibility can have a dramatic and chilling impact on patient care and research. The American Cancer Society urges the House to enact genetic information nondiscrimination legislation by taking prompt action on S. 1053, which represents a major step forward in ensuring that people do not face discrimination as a result of their medical or family history, while at the same time allowing medical research to advance.⁶¹

American Medical Association:

The AMA has a long-standing policy against genetic discrimination. This legislation would enable and encourage patients to take advantage of genetic screening, counseling, testing and new therapies resulting from the scientific advances in the field of genetics without worrying that such information could be used against them by their health insurers or employers.⁶²

American Osteopathic Association:

It is the position of the American Osteopathic Association that access to healthcare should not be restricted on the basis of genetic testing and that discrimination in employment on the basis of genetic testing should be prohibited. Patients must be able to discuss genetic testing with their osteopathic physicians without fear of discrimination from employers, potential employers, or healthcare plans for having undergone such testing or participating in clinical trials to test new therapies.⁶³

American Psychiatric Association:

As biomedical research advances, especially through the Human Genome Project, the possible abusive uses of genetic information will expand unless enforceable safeguards are enacted. A person's genetic information should only be used with his or her informed, voluntary, and non-coerced consent. Protecting patients' genetic information is critical to providing the highest quality medical care.⁶⁴

American Society for Human Genetics:

From the geneticist's point of view, the absence of a federal standard that prohibits employment and health insurance discrimination based on genetic information results in:

1. difficulty in recruiting subjects into genetic research studies;
2. patient avoidance of genetic services;
3. underutilization of genetic testing;
4. difficulty in obtaining insurance coverage when attempted;
5. several cases recognized that have not resulted in legal action; and
6. significantly increased time and effort in genetic evaluation and counseling sessions resulting in increased service costs⁶⁵

Biotechnology Industry Organization (BIO):

BIO has long supported national policies to ensure that individuals' personal medical information, including genetic information, is safeguarded against misuse. It is essential to assure the public that the great promise of biotechnology research will not be tarnished by abuses of this technology.⁶⁶

B'nai B'rith International:

[S]ome people, including many of the Ashkenazi Jewish women who have heard and read that they may be at risk for breast cancer because of their genes, are afraid that testing might expose them to discrimination by their insurers and even their employers...Having a genetic mutation linked to a disease is not a death sentence – many people with mutations will never even develop the associated disease. The decision whether to test for these mutations should be one made by individuals and families in consultation with their doctors and genetic counselors. This information can allow people to make better choices about everything from scheduling their first

diagnostic screening to diet and exercise. We should all be free to take advantage of these new information opportunities without fear of discrimination. When people are afraid of being branded by information, they don't get genetic counseling, and they don't get testing. They are even reluctant to participate in important scientific research studies that advance our ability to prevent, diagnose and treat any number of diseases.⁶⁷

Juvenile Diabetes Research Foundation:

As our understanding of human genetics moves forward, genetic testing will become increasingly used in health evaluation and prevention. It is important in this context to protect Americans from misuse of genetic information that would lead to discrimination in insurance coverage or employment. . . . Although the folly of discrimination based on genes would probably become clear to all at some point, it is preferable that laws be enacted to prevent such discrimination from ever occurring. In fact, categorizing people on a genetic basis in any context, whether it involves health care or any other aspect of social policy, violates the basic principles on which the United States was founded—that each individual is born equal and deserves equal treatment under law.⁶⁸

National Breast Cancer Coalition:

[C]omplex questions about insurance coverage and discrimination are raised by the availability of a genetic test for breast cancer. The National Action Plan and the Human Genome Project has held a two day Genetic Discrimination and Health Insurance Workshop at which women with the breast cancer gene would only agree to tell their stories under the strictest confidentiality agreement. Quite simply, they were afraid of the discrimination they would face with their employers and insurance companies if anyone knew they had this gene. . . . At present, there is no federal legislation that prevents insurance companies from denying coverage based on genetic status. While a few states have enacted laws, all of those provisions contain loopholes which, to varying degrees, undermine the intent of the legislation. Therefore, it is our position that any health care or insurance reform must include protections against discrimination in the provision of coverage based on genetic information, or predisposition to disease.⁶⁹

National Organizations of Rare Disorders:

Genetic information that is revealed to . . . insurance companies, employers and other family members may pose a risk to individuals – leading them to refuse genetic tests. Since there are no current government protections, nor prohibitions against genetic discrimination, individuals could be subject to severe psychological, emotional and financial risks. . . . Congress must act to ensure that the highest levels of protection are afforded to personally identifiable genetic information so that it can never be used against a person, nor accessed without a person's permission. Failure to guarantee protection of genetic information may lead to underutilization of genetic test, and discrimination against people with certain traits, which impacts Americans alive today, as well as future generations.⁷⁰

National Workrights Institute:

During the past several decades, our understanding of genetics has multiplied as procedures for identifying, analyzing, and manipulating DNA have advanced. Among the many benefits of these efforts are the ways they may influence preventive health, reproductive planning and eventually therapies to cure illnesses with a genetic component. No one can deny that this

knowledge may be a blessing in finding cures to diseases with genetic origins, including Alzheimer's, Huntington's and many forms of cancer. Nevertheless, the ability to identify individuals based on genetic characteristics necessarily predates the ability to use this information in the treatment of the corresponding diseases and therefore the immediate consequences of such advances have and will continue to lead to a number of forms of individual discrimination.⁷¹

Society for Women's Health Research:

Over the past several years, remarkable advances have been made in the field of human genetics that hold extraordinary promise for improving the health and quality of life of millions of Americans. The availability of this information can help people make informed decisions about prevention and treatment options, and allow them to live longer and healthier lives. However, the ability to determine genetic predisposition to disease can also have negative repercussions. Many people who might be helped by genetic testing are afraid to take advantage of this medical technology because of fears that their genetic information will be used against them. Of particular concern is the impact of genetic discrimination on the participation of women in clinical trials. Only recently have women been included in medical studies. Now, however, women will be reluctant to enroll in clinical trials if they fear that their medical information will be used against them by health insurers and employers. Without a guarantee of protection from genetic discrimination, all of the progress which has been made in ensuring that women have access to clinical trials will be of little value, and both women and research will suffer⁷².

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