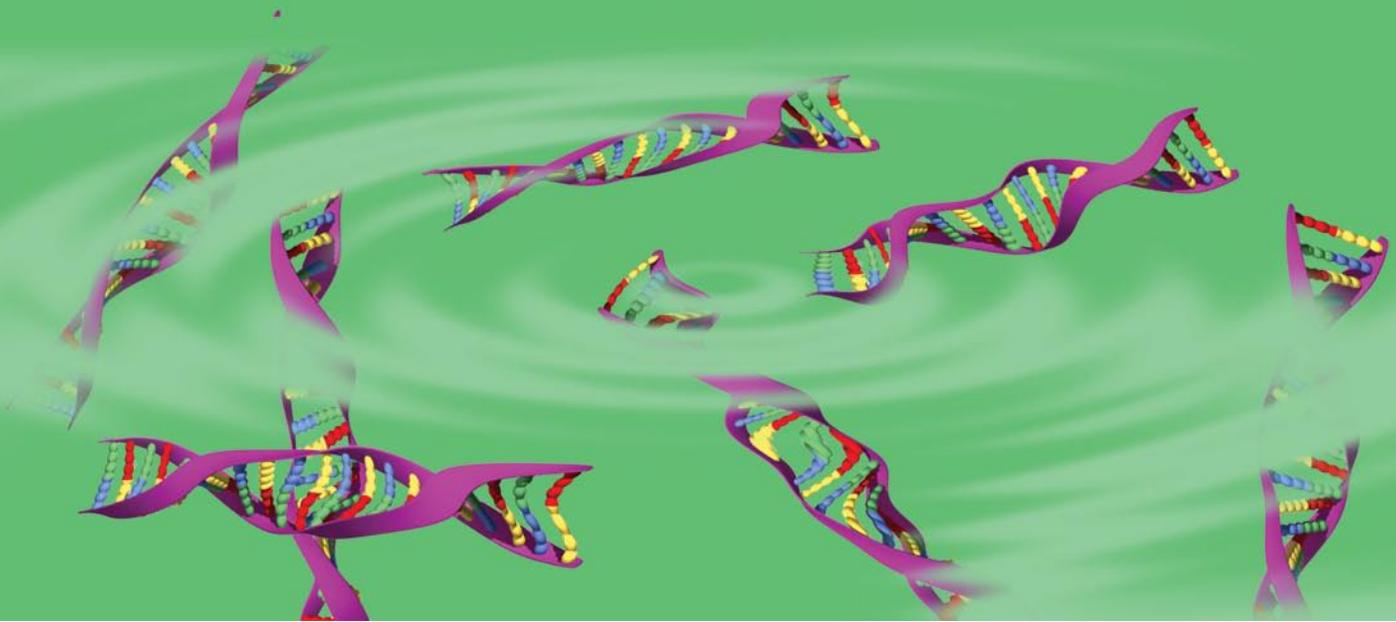


Plunging Into the Gene Pool

Even though the legal landscape has changed, concerns about the abuse of genetic testing persist.



BY ALISSA JOHNSON

Is your genetic information safe? Sixteen years have passed since Wisconsin Governor Tommy Thompson signed the first state law to prevent genetic discrimination in March 1991. A tidal wave of genetics legislation followed, propelled by the anticipated completion of the Human Genome Project to sequence and map the genes that make up a human being. Public fears continue, however, over the possible abuse of genetic testing technology.

Although genetic support groups and counselors often hear about cases of discrimination, few complaints have ever been filed. Almost all states restrict the use of genetic information in health insurance, and over half prohibit genetic discrimination in employment. The complexity of genetic discrimination laws and the difficulty of determining how they apply (depending, for example,

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on the type of genetic testing conducted, the genetic information acquired, the health status of the employee or insured, and how the information was used) may deter people who believe they were harmed from taking action. Furthermore, a given set of circumstances play out differently from state to state because the language of the laws varies. Without putting these laws to the test, it is too early to tell which states have followed a successful course.

DISCRIMINATION DOES HAPPEN

That's not to say that no one has faced and fought genetic discrimination. The story of Heidi Williams, who has alpha-1 antitrypsin (Alpha-1) deficiency, is an example of the abuse many Americans fear.

Because of a deficiency of the alpha-1 antitrypsin protein, people with Alpha-1 are susceptible to hepatitis, cirrhosis, emphysema and chronic obstructive pulmonary disease. When Williams applied for health insurance on behalf of her two healthy children, who

are carriers of only one copy of the gene for Alpha-1, coverage was denied based on their genetic makeup. As carriers, the Williams children are at little or no risk of developing the disease. Carriers may pass on the disease only if they have a child with another carrier. It is generally accepted that everyone carries three to eight recessive genes for serious genetic disorders, meaning everyone is potentially susceptible to the discrimination Williams experienced.

Through appeals and with the help of Alpha-1 experts, Williams provided information to the insurance company about what it means to be a carrier for Alpha-1. After repeated denials, the decision was finally reversed but only after the media reported the story.

"No one should have to force an insurance company to cover perfectly healthy children," Williams said in testimony to the Secretary's Advisory Committee on Genetics, Health and Society. "I should not have had to spend the better part of six months wondering if the decision to have my children's genetic status

verified by their pediatrician was a huge mistake.”

Williams says she is not alone. “Today, there is a current of fear reverberating throughout the genetic community,” she says. “It is not just a fear of loss, but it is a fear of retribution. It is a fear that forces many within this particular community to accept what should be unacceptable—discrimination by genetic status.”

Even Americans without an inherited disease share these fears, according to a 2006 survey conducted by Cogent Research. It found a majority of Americans had concerns about life and health insurance companies, the government, banks or financial institutions and employers gaining unauthorized access to personal genetic information.

SPECIAL PROTECTIONS

“Genetic tests are becoming more common in doctors’ offices and court cases, and there is surprisingly little regulation of how an individual’s genetic information is handled,” says Minnesota Representative Phyllis Kahn. “What are appropriate uses? Should genetic information be public? How long can the information be held in records?”

Representative Kahn tried to alleviate some of these concerns among her constituents. She says that six state agencies in Minnesota collect genetic information for purposes such as criminal justice, paternity testing and newborn screening. Kahn sponsored a bill to broadly address government data practices involving DNA. Her enacted legislation declares that genetic information is private data and allows its collection, storage, use and dissemination only as specified in a written informed consent given by the individual whose information is collected. The law permits exceptions to the consent requirements for certain circumstances, such as for criminal investigations.

Kahn says the nature of genetic information justifies special protections. “The

information locked in our DNA is not like other health information. Each individual’s genetic sequence is unique. Our DNA tells us about our parents and relatives. It also indicates certain medical conditions we have inherited or may develop in the future. This is not information we want to share with just anyone.”

STATE LAWS VARY

But not all states have headed down a similar path. During the Human Genome Project, consumers, health care professionals, policymakers, employers and insurers expressed concern about the possible abuse of genetic testing technology, particularly in light of public misconceptions about its true capabilities and limits. Many states subsequently enacted legislation to address discrimination and privacy concerns, but the pace of legislative activity has slowed.

Nearly all states restrict the use of genetic information to determine health insurance rates or eligibility. Fewer states have enacted legislation to prohibit genetic discrimination in employment (34) or to protect genetic privacy (32). State laws on the use of genetic information in life, disability and long-term care insurance are less common and tend to restrict rather than ban its use by, for example, requiring actuarial justification. Other states may have found that existing protections and privacy laws adequately address the issues raised by genetics.

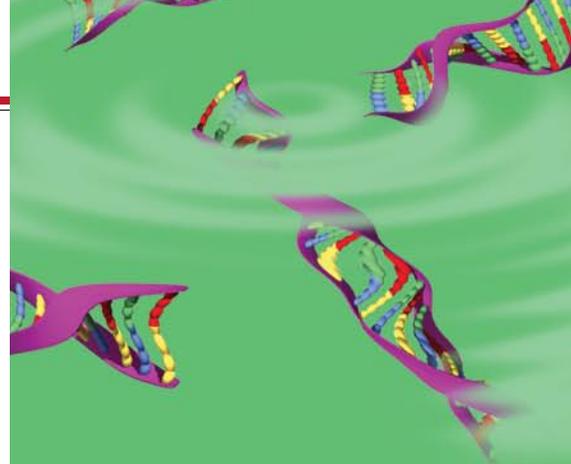
The impact that state genetics legislation will have on the public’s attitudes toward genetics, the legal system, progress in genetics research and the integration of genetic services into health care are still unclear. In the pioneering state of Wisconsin, the law may be acting as a deterrent against genetic testing discrimination, but it is difficult to tell. The Wisconsin Department of Workforce Development, which is responsible for enforcing the employment sections of the statute, teaches employers and labor orga-



REPRESENTATIVE
PHYLLIS KAHN
MINNESOTA



SENATOR
JOYCE BROADWORD
IDAHO



How Americans Feel

52%

Favor using individual genetic information to understand and improve health.

17%

Are afraid of genetic discrimination as a drawback of genomics.

66%

Are concerned about how their personal genetic information would be stored and who would have access to it.

30%

Say concerns about how genetic information would be stored and who would have access to it would prevent them from having a genetic test.

>50%

Are concerned about each of the following groups gaining unauthorized access to personal genetic information: life insurance companies, the government, health insurance companies, banks or financial institutions, and employers.

70%

Do not know whether there are laws that currently protect the privacy of their genetic information.

60%

Of the 18 percent who were aware of current laws responded that more protections are needed.

Source: Cogent Research, Cogent Syndicated Genomics Attitudes and Trends (CGAT), 2006.

At the Federal Level

Although Congress has not specifically addressed the use of genetic information in employment decisions, in 1995 the Equal Employment Opportunity Commission interpreted “disability” in the Americans with Disabilities Act to include genetic predisposition to disease. But this interpretation has yet to be tested in the courts. The commission has pursued just one complaint, which was settled in 2002. President Clinton banned genetic discrimination in the federal workplace via an executive order in 2000. And in 2003 and 2005, the U.S. Senate passed genetic nondiscrimination bills, but they never progressed in the House despite the Bush administration’s support.

Federal law, however, has had some impact on genetic testing and health insurance. The Health Insurance Portability and Accountability Act of 1996 prohibits insurers who provide health coverage for a group of 50 or more from denying an applicant because of a health factor, including genetic information. Insurers may restrict benefits or charge higher premiums, however. The law also prohibits exclusions for preexisting conditions for group health insurance as a result of a genetic predisposition to a particular condition.

Groups such as the Secretary’s Advisory Committee on Genetics, Health and Society, societies like the American College of Medical Genetics, and consumer advocates support efforts to protect genetic information in employment and health insurance. But other organizations such as the Chamber of Commerce have expressed concerns about federal legislation. These groups may object to such legislation given the lack of evidence that discrimination exists or the potential it creates for litigation.

NCSL RESOURCES ON GENETIC DISCRIMINATION AND PRIVACY

State Genetics Laws

www.ncsl.org/programs/health/genetics/charts.htm

State Genetics Legislation Database of 2004-2007 Bills

www.ncsl.org/programs/health/genetics/geneticsdb.cfm

State Laws Differ Widely

State discrimination and privacy laws range from broad to narrow. Factors determining the reach of protections include:

- ◆ The definitions of genetic information or genetic testing used in the statute, which may cover only predictive genetic information or genetic test results or extend to any information about genetic testing—including an invoice noting the receipt of genetic services, family history, inherited characteristics, or symptomatic or presymptomatic genetic conditions.
- ◆ The entities or individuals covered under the law, which may include some or all of the following: group insurers, individual insurers, employers, any person conducting a genetic test or accessing genetic information, and researchers.
- ◆ Consent provisions, which may involve simple written authorization or more detailed informed consent and may be required at different times such as when a genetic test is performed or when genetic information is disclosed.
- ◆ Exemptions such as the use of genetic information for criminal or civil justice matters, newborn screening or other public health activities and anonymous research.
- ◆ Enforcement provisions, which may stipulate mild or stiff civil penalties, and in rarer cases, imprisonment.

nizations about the genetic discrimination law through clinics. The public is informed through materials such as posters displayed in places of employment. Leanna Ware, civil rights bureau director for the Wisconsin Department of Workforce Development, says no one has ever filed a complaint of genetic discrimination by an employer, and the department receives few inquiries.

Perhaps this is because employers and insurers have no interest in the genetic information of their employees and members.

“It is pretty futuristic,” says Idaho Senator Joyce Broadsword who sponsored successful genetic discrimination legislation in 2006. “The insurance companies say that they are really not using genetic testing information, but I wanted to make sure that they were not going to in the future.”

A RESPONSIBILITY TO EDUCATE

Senator Broadsword and advocacy groups in her state worked to get out the message about the state’s new genetics legislation. “The American Cancer Society and the American Association of Retired Persons did a fairly comprehensive job of letting their members know about the law and what it covers,” she says. “I talked about it everywhere I went so that people knew it was enacted, and that if they wanted to find out about a possible predisposition to an illness, they could have a test without fear of reprisal.”

It may not be clear whose responsibility it is to educate consumers about genetics laws.

“Although health professionals might be presumed to be more knowledgeable, sometimes they are just as unaware as consumers about particular state laws unless they are working heavily in that area,” says Sharon Terry, executive director of the Genetic Alliance, an umbrella organization for genetics advocacy groups.

Reluctance to step forward about genetic discrimination also may account for the discrepancy between the fears expressed by the American public and the reality of few cases actually on record. According to some groups, Heidi Williams’ willingness to discuss her experience with genetic discrimination is rare. Terry says more protections are necessary in the form of “overarching legislation that allows individuals to feel comfortable about getting genetic testing.”

In addition to bringing genetic discrimination out in the open, national legislation may mitigate concerns about participation in clinical trials. Citizens may be particularly reluctant to join in trials where government involvement is real or perceived. (The federal government funds a significant amount of genetic research and development.) According to Terry, a drop off in clinical trial enrollment has occurred because of fear of discrimination.

Further action by lawmakers could protect Americans and help move science forward. “Consumers need to understand that in both employment and insurance, they are protected under the law,” Terry says. ■