

**GINA
PREVENTS
GENETIC
DISCRIMINATION**

ACT *of* PROTECTION

BY HEATHER BOERNER

Ray Stanhope may be the one in his family with hemophilia, but he's not the only one who deals with its ramifications. His sisters and niece sometimes fret about his health—Stanhope has severe hemophilia B—but they have medical concerns, too.

“They aren’t concerned for their own health,” he says. “The biggest thing for them has been the fear that they might be carriers and pass hemophilia on to their children. They worry that they’ll be denied health insurance because of it.”

Stanhope's family members aren't alone. Others in the bleeding disorders community wonder if a loved one's hemophilia or von Willebrand disease puts their children at risk of developing those disorders.

The good news is that with the help of newly developed genetic tests, science can answer many of these questions. And while some, including Stanhope's sisters, have been tested to see if they are carriers of hemophilia, many have hesitated.

"Sometimes people will pay out-of-pocket for genetic tests and keep the results a secret from the healthcare professionals so the results stay out of their medical records," says Susannah Baruch, JD, director of law and policy at the Johns Hopkins University Genetics and Public Policy Center in Washington, DC.

There has been good reason for this fear, says Stanhope, chair of the National Hemophilia Foundation's (NHF's) board of directors. In a community that has to navigate lifetime insurance caps and precarious insurance coverage, many fear they or their children will be discriminated against. Some community members are concerned that health insurers will use genetic information to deny membership or claims, to raise premiums or to avoid covering pregnancy. Others worry that employers won't hire them if they are known carriers for hemophilia, with the potential to have children who will need costly medical care.

"Hemophilia is certainly one of the most expensive chronic illnesses you can have," says Stanhope, 53, of Sugar Land, Texas. "The sisters or daughters of people with hemophilia, who have seen family members denied health insurance, are reluctant to stand out in any way."

But things are changing. By this time next year, genetic information protection will be the law of the land. The Genetic Information Nondiscrimination Act (GINA), which goes into effect in November 2009, will ensure that people with genetic markers for medical conditions, including bleeding disorders, can't be denied health insurance or refused employment because of their genetic predisposition or carrier status. It will also prevent health insurers from classifying genetic predispositions or carrier status as pre-existing conditions and refusing to cover affected people.

"GINA is an acknowledgment that genetics, like race or gender or ethnicity or age, are protected," says MK Holohan Quattrocchi, JD, senior health policy analyst at the National Human Genome Research Institute of the National Institutes of Health. "It's truly an important recognition."

UNLOCKING THE POTENTIAL OF GENETIC TESTING

Until the passage of GINA, people weren't protected from discrimination based on their genes, and the potential for gene-based care has gone largely untapped. Since people were afraid to be tested, says Quattrocchi, clinical trials were hampered. This frustrated clinicians, especially



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when the people refusing the tests were at significant risk of developing a disease based on their family histories, he says.

"Those families wouldn't participate in research because they were afraid of losing their insurance," recalls Quattrocchi. "And researchers couldn't tell them discrimination wasn't a possibility." The courts have presided over a handful of cases of genetic discrimination, says Baruch. While there have only been a few cases of documented genetic discrimination, US Rep. Judy Biggert (R-Illinois) says the fear of such discrimination has left people unwilling and unable to take advantage of medical breakthroughs.

"Gene-based care is going to change the way we look at medicine, from treatment to preventive medicine and personalized care," says Biggert, who co-sponsored GINA with Rep. Louise Slaughter (D-New York). "It will allow people in the bleeding disorders community to make more informed

choices about healthcare for themselves and for their children.” The hope, she says, is that GINA will also eventually lower medical costs by keeping people healthy longer.

WHAT GINA DOES

Healthcare and employment protections are a patchwork of laws, including the Americans with Disabilities Act and the Health Insurance Portability and Accountability Act (HIPAA). GINA patches a number of gaping holes in those protections, particularly individual coverage.

HIPAA protects people with group coverage from genetic discrimination by allowing them to keep their current health insurance after leaving a job. This helps people avoid gaps in coverage that could increase costs or prevent them from getting coverage at all. It also explicitly prohibits genetic discrimination. However, if you want to become self-employed or find yourself in a job without coverage, you will face an individual insurance market that currently offers only spotty, state-by-state protection for your genetic information.

GINA changes that. Starting May 21, 2009, the law prohibits health insurers from using genetic information to increase healthcare premiums or co-pays, or as a basis for deciding whether to cover someone. It also prohibits insurers from requiring genetic tests as a term of coverage. By November 21, 2009, the law will extend to employers, prohibiting them from using genetic information as a basis of employment, promotion or job change. Further, GINA makes it illegal for employers to compile genetic information on their employees.

“This law sends a clear message first to employers and insurers that if they’ve used genetic information in the past or are thinking about it, they may not do this,” says Glenn Mones, vice president for public policy at NHF. “Second, it’s universal—it’s not a matter of whether insurers can get away with discrimination in this state or that state.”

Most importantly, the law allows tougher state regulations against genetic discrimination such as Vermont’s to stand, while overriding weaker or more vague genetic discrimination laws. For instance, notes Quattrocchi, previous state laws against genetic discrimination have excluded from coverage chemical tests, a vague term that has stymied experts in genetic testing because all genetic tests use chemicals to produce results. The Equal Employment Opportunity Commission and the Department of Health and Human Services will regulate the new law. Enforcement has yet to be determined, as officials continue to write the regulations.

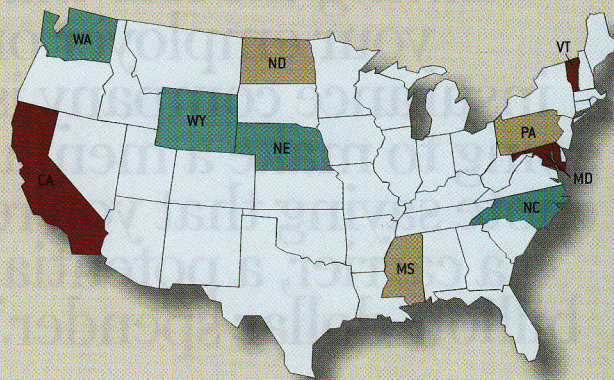
WHAT GINA WON'T DO

Some critics say GINA is incomplete. It doesn’t, for instance, prohibit discrimination once a person develops a genetic illness or condition. In other words, individual market insurers can still refuse to cover a child with hemophilia born to a carrier mother or raise premiums if someone develops an acquired form of von Willebrand disease later in life.

In addition, GINA doesn’t prohibit employers from collecting genetic information for use in employee wellness

WHAT YOUR RIGHTS ARE NOW

Even though GINA hasn’t gone into effect yet, your state may already protect you from some forms of genetic discrimination. Right now, 35 states prevent workplace discrimination based on genetic information, and 47 prevent health insurance discrimination based on genetic risk factors. The type of coverage depends on the state; many offer moderate protections. The following are the states with the best and worst protections:



■ THE BIG WINNERS:

VERMONT, CALIFORNIA AND MARYLAND

If you live in these states, you’re subject to the most comprehensive genetic protections in the country. The California law, for instance, applies to both group and individual insurance, prohibits insurers from using genetic information to decide whether to insure you, may not require you to take a genetic test as a term of coverage and may not share your genetic information without your specific consent. Maryland’s law additionally prevents insurers from using genetic information to increase your premiums.

■ THE SLIM PICKINGS:

WASHINGTON, WYOMING, NEBRASKA AND NORTH CAROLINA

If you live in these states, your protections are among the most limited in the country. For instance, Washington’s law only prohibits insurers from disclosing your genetic information without your consent. Wyoming and North Carolina prohibit insurers from using your genetic information to decide whether to offer you insurance, but don’t cover any other type of genetic discrimination. Nebraska only prohibits insurers from requiring you to take genetic tests.

■ THE SILENT STATES:

MISSISSIPPI, NORTH DAKOTA AND PENNSYLVANIA

These states have no genetic discrimination protections in place.

Most of these laws are untested, so it’s hard to know how strong they are, says Michael S. Watson, PhD, executive director of the American College of Medical Genetics, a nonprofit professional group for geneticists located in Bethesda, Maryland.

“That’s the fundamental problem with a lot of these laws—there’s a lot of nuance here,” he says.

For information on your state, visit the National Conference of State Legislatures’ Web chart: www.ncsl.org/programs/health/genetics/ndishlth.htm

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programs or in monitoring the health effects of working with toxic material. However, it does prohibit employers from disclosing this information and using it against their employees or to discharge an employee. Further, it also doesn’t extend to life, long-term care or disability insurance. Stanhope says he hopes it eventually will.

“Eventually, we would like to see some way of improving that protection, given that care today allows more people with hemophilia to live a normal life span, go to school and become tax-paying citizens,” Stanhope says. “These are battles we have to fight in small chunks. The key is to find areas where we can make inroads.”

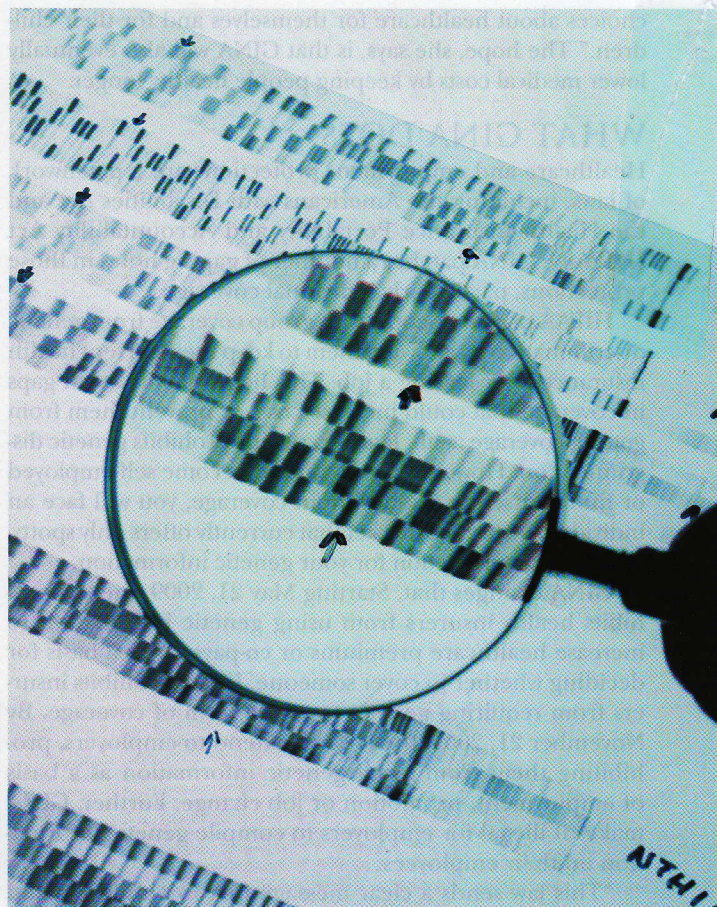
HOPE FOR THE FUTURE

Still, the power of GINA remains. When Leslie Situ, 21, of Oakland, California, moved to the US from China in 1996, she didn’t understand why her father stayed in bed for days at a time. The family didn’t learn that Situ’s father had severe hemophilia A until they moved to the San Francisco Bay Area, where Situ’s aunt, a carrier, took them to a hemophilia treatment center for the first time. That’s when Situ received the genetic test that told her what seemed to be inevitable: She’s a carrier.

The news didn’t mean much to Situ at the time, she says. As a nine-year-old, she didn’t have to worry about health coverage and she wasn’t in the market for a job. But now, as she completes her bachelor’s degree in political economy at UC Berkeley, the meaning of her genetic propensity is becoming clear. And so is the importance of GINA.

When Situ first heard about GINA, she didn’t perceive its implications for her. But later she thought, “‘This really makes sense for me.’ It put it in the back of my mind: What if some employer or insurance company looks at the hemophilia in my family and says, ‘Oh, sorry, you can’t have insurance because your kid is going to have it.’”

For two years, Situ campaigned on Capitol Hill in favor of GINA’s passage during NHF’s Washington Days. She



PETER DAZELEY/GETTY IMAGES

told legislators, she says, that this law will protect her as she leaves her university health insurance and starts her adult life.

“I certainly feel like knowledge is power,” Situ says. “GINA allows you to get tested without having the fear that your employer or insurance company is going to make a mental note saying that you’re a carrier, a potential billion-dollar spender. Just for that fact, and the self-awareness of your own body that comes from getting tested, it’s already priceless.” ●

To Learn More...

- For more information about genetic testing for hemophilia, contact HANDI, NHF’s information resource center: 800.42.HANDI or handi@hemophilia.org.
- Visit www.geneticalliance.org, the Web site of the Genetic Alliance, a collaboration of organizations, including NHF, that advocated for GINA’s passage.
- Visit the home of the National Genome Research Institute, part of the National Institutes of Health, for a timeline of GINA’s 12-year evolution: www.genome.gov/24519851.
- Advocate for other bills that will help people in the bleeding disorders community by getting involved with NHF’s next Washington Days, to be held March 4–6, 2009. For more information, contact NHF’s Department of Public Policy: 212.328.3700.