

Summary

For more than a decade, experts have called on Congress to enact comprehensive legal prohibitions on genetic discrimination in health insurance. Fear of genetic discrimination can discourage patients from undergoing genetic testing or participating in genetic research studies. Such fear threatens to deter advances in the field of genetic testing and may limit the realization of benefits of genetic testing.

A prohibition on genetic discrimination challenges a key construct in medically underwritten health insurance: in return for premium payments, insurers promise to protect consumers against the cost of unknown future medical risks. Insurers use medical underwriting to distinguish known risks that will not be covered. Eventually genetic testing may render this construct obsolete and all people may be able to discover their future health risks, rendering us all “uninsurable.” For today, however, GINA would protect our genetic information because its importance is so profound. By protecting our insurability, GINA also makes it more likely that advances in genetic science will discover more effective treatments, cures, and preventive therapies.

Recent research examined medical underwriting practices of individual health insurance companies in response to genetic information. An examination of actual instances of genetic discrimination in the individual market is impractical because the science of genetic testing is young and relatively few individuals have undergone predictive genetic testing. Our research asked individual health insurers to medically underwrite hypothetical applicants. Four pairs of applicants were presented; within each pair, one applicant had received a positive genetic test result indicating elevated risk of future disease. In seven instances, five of the 23 responding medical underwriters said they would take an adverse action based on genetic information. They would deny coverage, surcharge premiums, and impose exclusion riders to limit covered benefits.

Underwriters were also asked what actions they would take based on an applicant’s receipt of genetic services. Specifically, they were asked to consider an applicant with a *BRCA1* mutation whose doctor had discussed or recommended preventive surgery to reduce her future risk of cancer. Thirteen underwriters responded to this question. Of those, five said they would take an adverse action based on discussion of risk reducing options. Ten said they would act on a physician’s recommendation of such options. Again, underwriters would deny coverage, surcharge premiums, or impose exclusion riders to limit covered benefits.

Congress and 43 states have enacted laws to prohibit genetic discrimination in health insurance, at least in some instances. Federal legislation is needed to ensure comprehensive protection against all forms of discrimination in all health insurance coverage – whether employer sponsored or individual, and whether regulated by states or the federal government.

Testimony of Karen Pollitz
Research Professor
Georgetown University Health Policy Institute
on
Genetic Discrimination in Health Insurance

U.S. House of Representatives
Committee on Energy and Commerce
Subcommittee on Health

March 8, 2007

Chairman Pallone, Representative Deal, and Members of the Subcommittee, thank you for this opportunity to testify on HR 493, the Genetic Information Nondiscrimination Act (GINA) of 2007. My name is Karen Pollitz. I am a health policy researcher and adjunct professor of public policy at Georgetown University. My field of expertise is private health insurance regulation, and my remarks today will focus on issues addressed in Title I of HR 493, which prohibits genetic discrimination in health insurance, as well as on findings of a recently completed study of medical underwriting and genetic information in the individual health insurance market.

For more than a decade, scientific and public policy leaders, including the Secretary's Advisory Committee on Genetics, Health, and Society, have called on Congress to enact comprehensive legal prohibitions on health insurance discrimination:

“[The Committee] heard from many Americans who are concerned about the misuse of genetic information by third parties, such as health insurers and employers, and the potential for discrimination based on that information. Many stated that fear of genetic discrimination would dissuade them from undergoing a genetic test or participating in genetic research studies. Others stated they would pay out of pocket for a genetic test to prevent the results from being placed in their medical record. Such concerns are a deterrent to advances in the field of genetic testing and may limit the realization of the benefits of genetic testing.”¹

Without question, a prohibition on genetic discrimination challenges a key construct in medically underwritten health insurance. In return for premium payments, insurers promise to protect consumers against the cost of unknown, future medical risks. Insurers use medical underwriting to distinguish known risks that will not be covered. Eventually, scientific advances may render this construct obsolete, and all people will be able to discover one or more of our future health risks through genetic testing – rendering us all “uninsurable.” By protecting our

insurability, however, GINA also makes it more likely that the medical benefits promised by genetic science come to pass with the discovery of more effective treatments, cures, and preventive therapies for many serious and expensive health conditions.

Current law prohibitions are incomplete

Congress and the states have already gone a long way toward ending genetic discrimination in health insurance, though work remains to be done. There is not yet comprehensive protection against genetic discrimination in health insurance. Comprehensive protection will prevent all health plans and health insurers in all markets from turning people down, charging them more, or excluding or limiting covered benefits based on genetic information. Only federal legislation can accomplish this goal.

In 1996, Congress enacted the Health Insurance Portability and Accountability Act (HIPAA), setting federal minimum standards for private health insurance, including a requirement that employer-sponsored group health plans may not exclude participants based on genetic information or other factors relating to health status. HIPAA also prohibited group health plans from imposing pre-existing condition exclusion periods based on genetic information. However, HIPAA did not prohibit individual market health insurers from underwriting on the basis of genetic information, nor did it limit insurers in any market from varying premiums on that basis.

Since HIPAA, 43 states have prohibited use of genetic information by individual market health insurers. (See Appendix A) Most have enacted statutory prohibitions, which vary. Some state laws, for example, prohibit medical underwriting based on genetic test results, but not on family history. A few states prohibit insurers from denying coverage based on genetic information, but permit premiums to be surcharged. Interestingly, most state insurance regulators would enforce a broader prohibition on genetic discrimination than plain statutory language might

otherwise indicate. For example, most say insurers cannot underwrite based on family history, even when this is not specifically included in the state law definition of genetic information. However state laws do not apply to group health benefits offered by so-called self-insured employer plans because a federal law called ERISA preempts state regulation in this area.

Comprehensive prohibition of genetic discrimination in health insurance is needed.

Some in the insurance industry have testified that federal legislation is not necessary, arguing that there is no evidence that insurers engage in genetic discrimination.²

According to one industry expert,

"There is good research out there showing that people *believe* employers, health insurers, doctors and the family dog are using genetic information against them. [But] health insurers are not using genetic information. There is a very real public fear but it is unfounded. That information is not being used against people today."³

However, it is unlikely that medical underwriters in health insurance have had many opportunities to discriminate based on genetic information. The science of genetic testing is still young, and relatively few individuals have undergone predictive genetic testing in the U.S. For example, genetic testing for hereditary breast/ovarian cancer via *BRCA1* and *BRCA2* testing is one of the better known and more widely used predictive genetic tests. Since this genetic test became clinically available in the mid 1990s, about 75,000 individuals have been tested through the commercial lab which holds the patents on these genes, and approximately 9,000 have received positive test results.⁴ Many, if not most of those patients with positive test results likely were insured by employer-sponsored group health plans, where discrimination based on health status is already largely prohibited.

Even so, as causative genes associated with increased susceptibility to common diseases, such as asthma, heart disease, and cancer are identified, the number of tested individuals will grow considerably. It is therefore important to understand how health insurers would respond to

genetic information about applicants for coverage when they encounter this information in the medical underwriting process.

Background on Medical Underwriting

Individual health insurance plays a small but important role in our nation's system of health coverage. People often turn to this market when they cannot get health benefits from an employer or when they are ineligible for public programs such as Medicare or Medicaid. In 2005, over 17 million people in the U.S. were covered by individual health insurance, or 6.6 percent of the non-elderly population.⁵ On average, over a three-year period, one in four adults buys or seeks individual coverage.⁶

Individual health insurance is medically underwritten in most states. This means applicants for coverage must submit information about their current and past health status – for example, whether they have been diagnosed with medical conditions such as diabetes, dates of and reasons for recent physician visits, names and dosages of recently prescribed medications, etc. Health insurance applications typically do not include specific questions about genetic test information nor about family health history.

On as many as half of individual health insurance applications, underwriters make a decision to issue or decline coverage based solely on health status information provided on the application.⁷ For other applicants, additional information may be required. All applications for medically underwritten health insurance policies require written consent to release any medical records and to submit to further medical examinations that may be requested. Most often additional medical information will be sought directly from the applicant (for example, a telephone interview to determine results of a recent pap test), or her physician. Less frequently, applicants may be required to take a physical examination or submit samples of urine, blood, or saliva for testing. A 2001 report on medical underwriting practices found that in the course of 420 applications for coverage studied, underwriters requested further specific medical histories

179 times, attending physician statements and/or copies of patient medical records 140 times, samples of blood, saliva, or urine for laboratory testing 46 times, and paramedic physical examination of the applicant 21 times.⁸ Other experts on individual health insurance market underwriting suggest patient medical records are typically requested on 20 percent of applications, while a very small portion of insurers (estimated at fewer than one-in-ten) may request records on more than 40 percent of applications.⁹ It is in this additional investigation of an applicant's medical history and health status that information about genetic testing is likely to be discovered. Underwriters can come across medical information they did not specifically seek. Once disclosed, however, they are obliged to consider, evaluate, and act upon all available information.

The actions underwriters may take on an application fall into three main categories.

- Coverage may be offered, or the applicant may be turned down.
- If offered, coverage may be priced using a standard rate premium, or a premium surcharge may be applied.
- If offered, the policy may include all covered benefits, or certain benefits may be specifically limited or excluded. For example, the insurer may apply an exclusion rider,¹ or increase the policy's annual deductible.

Underwriter responses to genetic information

Last year, my colleagues and I partnered with Beth N. Peshkin, a senior genetic counselor and associate professor of oncology at Georgetown's Lombardi Comprehensive Cancer, to conduct a study of medical underwriting practices in the individual health insurance market as they relate to genetic information. Our team also worked with private risk management

¹ An exclusion rider is an amendment to the insurance policy that specifically excludes coverage for a named health condition. Sometimes exclusion riders also eliminate coverage for body parts or systems that a health condition might affect.

consultants to design and implement this study. This project was supported by a grant from the Nathan Cummings Foundation.

Professional medical underwriters from 23 insurers – some local and some multi-state – volunteered to participate in a survey about medical underwriting practices and genetic information. Survey participants were senior health underwriters from 23 companies that sell individual health insurance. Sixteen worked for national, commercial insurers that write coverage in multiple states; seven worked for nonprofit Blue Cross Blue Shield plans. The size of participating insurers varied, though according to data from the National Association of Insurance Commissioners, three of the participating insurers rank among the top ten health insurance companies based on national market share, and eight rank among the top 25 companies.¹⁰ Participants and their employing insurers were promised anonymity.

Our survey asked participants to underwrite eight hypothetical applicants for coverage. The applicants were arranged in pairs that were almost identical except one person in each pair had received a positive genetic test result. For each pair of applicants, medical information was provided that would likely prompt further investigation by underwriters. The survey noted when genetic test result information was discoverable via patient medical records or other follow up inquiry. The hypothetical applicants presented in the survey were:

- Ann and Brenda -- healthy 29-year-old women who receive regular annual mammograms well before the age of 40 when such screening is recommended for the general population. Upon review of medical records, it is clear that both Ann and Brenda have a family history of breast cancer. In addition, Brenda has inherited a *BRCA1* mutation, meaning her lifetime risk of breast and ovarian cancer is significantly elevated, though not certain.
- Clarice and Donna -- 48-year-old women who are ten-year breast cancer survivors. Both women recently had preventive surgery to remove their ovaries. Upon review of medical records, it is clear that Donna's reason for undergoing surgery was a

genetic test result from 2003 which was positive for mutation in the *BRCA1* gene, meaning her lifetime risk of a second breast cancer is significantly elevated, but not certain.

- Evan and Fritz -- 52-year-old men in good health. Both receive regular blood tests to monitor blood iron levels. In follow up telephone interviews both men acknowledge a close family history of Hemochromatosis, though blood tests for both men have consistently been negative for elevated blood iron levels. Fritz has also undergone genetic testing with a positive result, meaning his blood iron levels may eventually increase and need to be managed.
- Galen and Howard -- 44-year-old men in excellent health. Both of their insurance applications disclosed a recent consultation with a cardiologist, and both take several nutritional supplements daily. Medical records indicate Galen sought his checkup after a neighbor his age died suddenly of a heart attack. Howard's visit was prompted by an online genetic testing company report that said he has gene variants that put him at risk for heart disease. The cardiologist questioned the validity of the tests and assured him the gene variants found are commonly observed in most people.

Survey participants were asked what underwriting action(s) they would take in response to each of the hypothetical applicants. Five of the 23 underwriters responded in seven instances that they would treat applicants differently because of their genetic information. For Brenda, the hypothetical applicant with a *BRCA1* mutation, insurers # 7, #8, and #23 said they would, respectively, offer Brenda coverage at a surcharged premium, deny her application, and offer a policy with a rider excluding coverage for all diseases and disorders related to her breasts. For hypothetical Donna, a ten-year breast cancer survivor with a *BRCA1* mutation, insurer #11 would reject her application. Insurer #1 said consideration of the application from hypothetical Fritz

would be postponed pending provision of additional medical information, while insurer #8 would deny Fritz's application. Finally, insurer #8 would postpone consideration of Howard's application pending provision of additional medical information.

In addition to these actions, in two other instances underwriters (for insurers #7 and #21) were uncertain as to the appropriate underwriting action and said they would need to consult their medical directors. (See Table 1)

The good news is that most underwriters said most of the time that they would not act based on genetic information. Most said this is because their company policy is to underwrite on the basis of a definitive diagnosis and treatment, and they do not underwrite on the basis of family history or genetic information in the absence of a diagnosis. Most underwriters believed their company policy had been adopted pursuant to laws prohibiting this practice. (Those from multi-state insurers said their company's policy would apply even in those states that have not yet enacted legislation.)

Nevertheless, survey findings are also consistent with patient and policymaker concerns that genetic discrimination in health insurance can happen today and could pose a problem in the future. When asked whether they would take adverse action based on genetic information in the absence of legal prohibitions, many underwriters answered yes.

Underwriter responses to genetic services

Legislation before you today also prohibits health insurance discrimination based on receipt of or request for genetic services – a term which includes genetic counseling to interpret or assess genetic information. Some patients with inherited risk of disease today have options – ranging from lifestyle changes to preventive therapies or surgery – to reduce that future risk and may consider those pursuant to genetic testing. As part of our research, we asked underwriters to participate in a follow up survey that also tested their reaction to genetic services. The follow up

Table 1. Underwriter Response to Hypothetical Applicants With Genetic Information
[Applicants *italicized* had positive genetic test results]

Insurer	Ann	<i>Brenda</i>	Clarice	<i>Donna</i>	Evan	<i>Fritz</i>	Galen	<i>Howard</i>
1						Pend. Unable to offer without diagnosis.		
2								
3								
4								
5								
6								
7		Premium surcharge (25%)						Unsure. Would refer to Medical Director.
8		Deny				Deny		Pend until further evaluation completed
9								
10								
11				Deny				
12								
13								
14								
15								
16								
17								
18								
19								
20								
21								Unsure. Would refer to Medical Director.
22								
23		Rider disease/dis order of breast						

Note: Table shows only those underwriting actions which differed between applicant pairs based on genetic information.

survey sought additional information about one of the hypothetical applicants with a *BRCA1* mutation, who would also have been counseled about options for reducing her inherited risk of breast and ovarian cancer. Underwriters were asked, “If Donna’s medical records indicated her doctor had discussed or recommended options to reduce her risk of future breast cancers (for example, prophylactic surgery) what underwriting actions would you take on her application?”

Only 13 underwriters responded to these follow up questions. Of those, five indicated they would take an adverse action in response to Donna’s doctor having discussed risk reducing

options, while ten of 13 said they would take an adverse action if the doctor recommended a significant medical procedure to reduce inherited risk. (See Table 2) Interestingly, when the same question was posed to state insurance regulators, most said their laws would also protect against genetic discrimination based on these kinds of patient-physician communications. (See Appendix B)

Table 2. Underwriting Actions for Donna Based on Interventions to Reduce Breast Cancer Risk (Counseled vs. Recommended)

Insurer	Underwriting Action	
	Doctor discussed prophylactic surgery to reduce risk	Doctor recommended prophylactic surgery to reduce risk
1		Postpone
2	Probably Rider	Probably Rider
4	Rate	Rate
6	Rider	Rider
7		Rider or Deny
10		Deny
11	Deny	Deny
12		Rider
14		
15		
16		Postpone
17	Deny	Deny
20		

Limitations of Methodology

The small number of self-selected survey respondents means results cannot be interpreted as representative of the entire health insurance industry. In addition, because the survey asked questions about only three genetic tests, results provide no information about how underwriters might respond to other types of genetic information or inherited risks. Other study design aspects may have biased results. For example, survey respondents came from a self-selected sample of those who participate in a professional underwriting study group and who tend to be more senior, expert, and informed about issues. In addition, the survey clearly identified the issue being studied, potentially biasing respondents to answer “correctly.” On the other hand, survey

vignettes also made obvious applicants' genetic information. Therefore results do not shed light on how well underwriters recognize, or overlook, this information when they encounter it in practice. Nevertheless, the responses of so many mainstream insurers provide important insights into industry underwriting practices related to genetic information.

Policy implications

Industry experts and others have urged that health insurance discrimination based on genetic information happens rarely, if at all, today, and there is evidence to support this contention. The low incidence of predictive genetic testing in the general population is one key reason. In addition, prohibitions in more than 40 states may discourage insurers from actively seeking out information about applicants' genetic status or from acting upon such information when it is discovered in the course of underwriting. Most carriers surveyed said they do not underwrite based on genetic information.

However, findings showed that some individual market insurers would act on genetic information if they discovered it. In seven of the 92 decisions tracked by this study, an insurer used genetic information as the basis for their action to decline/postpone, limit coverage or surcharge premiums. These seven decisions were limited to five of the 23 insurance carriers and were spread across all four applicants with genetic information. One of these respondents expressed uncertainty as to the meaning of one of the genetic tests. Experts in the field of genetics have long called for "vigorous educational efforts" within the insurance industry to improve understanding about genetic information. Findings from this study suggest such education could be beneficial. Comprehensive federal legislation could also reinforce and strengthen state restrictions and promote a uniform standard within the health insurance industry to never use genetic information in medical underwriting.

From the insurer perspective, medical underwriting in individual health insurance is based on a key premise: the insurer promises to cover an individual's future health care risks, but

only if the applicant discloses known risks today. Public policy has insisted on an exception for genetic information – protecting this information, at least partially, because the clinical significance and promise of this science is so profound. Policymakers will have to decide how comprehensive and uniform protections should be. In so doing, they will have to consider the problem of health insurance discrimination in light of what genetic testing means for patients today and what it is likely to mean in the future. Advances in genetic science may make possible dramatic improvements in medicine and public health that can reduce or prevent the incidence of many serious and expensive health conditions. For that day to come, patients will need assurances that they can both learn their genetic status and take appropriate actions to reduce their risk and improve their health without endangering their insurability.

APPENDIX A
State Prohibitions on Use of Genetic Information in Medical Underwriting,
Individual Health Insurance Market

Prohibited Underwriting Action												
State	Application asks about:			Deny coverage based on:			Raise premium based on:			Exclusion rider based on:		
	Family history	Received genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referred for genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referred for genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referral for genetic services (incl. counseling or testing)	Positive genetic test results
AL ⁺						√			√			√
AK												
AZ ⁺					X	√		X	√		X	√
AR ⁺		X	X		X	X		X	X		X	X
CA ⁺			√			√			√	√	√	√
CO		X	√	X	X	√	X	X	√	X	X	√
CT	X	X	X	X	X	√	X	X	√	X	X	√
DE				X	√	√	X	√	√	X	√	√
DC	X	X	X	X	√	√	X	√	√	X	√	√
FL		√	√	X	√	√	X	√	√	X	√	√
GA						√						√
HI	X	X	√	X	√	√	X	√	√	X	√	√
ID			√		X	√		X	√	√	√	√
IL ⁺	X	X	√	X	X	√				X	X	√
IN		X	√	X	√	√	X	√	√	√	√	√
IA												
KS		√	√	X	√	√	X	√	√	X	√	√
KY			√		√	√		√	√	√	√	√
LA	√	√	√	√	√	√	√	√	√	√	√	√
ME				√	√	√	√	√	√	√	√	√
MD	X	X	√	X	√	√	X	√	√	X	√	√
MA	X	X	X	√	√	√	√	√	√	√	√	√
MI		√	√	X	X	X	X	X	X	√	√	√
MN		√	√		√	√		√	√	√	√	√
MS												
MO ⁺		X	X	X	X	X	X	X	X	X	X	X
MT			√		X	√		X	√	X	X	√
NE												
NV		√	√	X	√	√	X	√	√	X	√	√
NH		√	√		√	√		√	√	X	√	√
NJ	√	√	√	√	√	√	√	√	√	√	√	√
NM				√		√	√		√	√		√
NY				√	√	√	√	√	√	√	√	√
NC		X	X	X	X	√	X	X	√		X	X
ND					X			X			X	

Prohibited Underwriting Action												
State	Application asks about:			Deny coverage based on:			Raise premium based on:			Exclusion rider based on:		
	Family history	Received genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referred for genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referred for genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referral for genetic services (incl. counseling or testing)	Positive genetic test results
OH			√			√			√			√
OK ⁺				X	X	X	X	X	X	X	X	X
OR	√	√	√	X	X	√	√	√	√	√	√	√
PA	**	**	**	**	**	**	**	**	**	**	**	**
RI	X	√	√	X	√	√	X	√	√	X	√	√
SC				X	√	√	X	√	√	X	√	√
SD												
TN		X	√		√	√		√	√		√	√
TX				X	X	√	X	X	√	X	X	√
UT		√	√	X	√	√	X	√	√	X	√	√
VT				√	√	√	√	√	√	√	√	√
VA				X	√	√	X	√	√	X	√	√
WA	√	√	√	√	√	√	√	√	√	√	√	√
WV												
WI		√	√		√	√		√	√		√	√
WY				X	X	X	**	**	X	**	X	

Source: Statutory research by Georgetown University and responses of state insurance regulators to Georgetown survey conducted in May-June, 2006. Regulators in five states did not respond to the survey: California, Mississippi, New Mexico, New York, and Vermont. In these states, table only indicates prohibitions found in statutory language.

√ indicates prohibition found in state statute.

x indicates state regulator confirms practice is prohibited, but practice is not specified in statute.

** Regulator did not answer this question. No statutory prohibition found.

+ Additional state notes below:

Alabama prohibitions only apply to genetic information about risk of cancer.

Arizona prohibitions unless “applicant’s medical condition and history and either claims experience or actuarial projections establish that differences in claims are likely to result from the genetic condition.”

Arkansas prohibitions apply “except to the extent and in the same fashion as an insurer limits coverage or increases premiums for loss caused or contributed to by other medical conditions presenting an increased risk.”

California prohibits insurers from denying “enrollment or coverage to an individual solely due to a family history of breast cancer, or who has had one or more diagnostic procedures for breast disease but has not developed or been diagnosed with breast cancer.”

Illinois allows an insurer to “consider the results of genetic testing...if the individual voluntarily submits the results and the results are favorable to the individual.”

Missouri prohibits insurers from inquiring “to determine whether a person or blood relative of such person has taken or refused a genetic test or what the test results of any test were...” except with approval of the applicant to consider this type of information.

Oklahoma prohibitions apply “except to the extent and in the same fashion as an insurer limits coverage or increases premiums for loss caused or contributed to by other medical conditions presenting an increased risk.”

APPENDIX B
State Prohibitions on Use of Genetic Information in Medical Underwriting,
Individual Health Insurance Market

Prohibited Underwriting Action						
State	Deny coverage based on:		Raise premium based on:		Exclusion rider based on:	
	Physician discusses risk reduction options	Physician recommends risk reduction options	Physician discusses risk reduction options	Physician recommends risk reduction options	Physician discusses risk reduction options	Physician recommends risk reduction options
AL ⁺	X	X	X	X	X	X
AK						
AZ ⁺						
AR ⁺	X	X	X	X	X	X
CA ⁺					√	√
CO	X	X	X	X	X	X
CT	X	X	X	X	X	X
DE	X	X	X	X	X	X
DC			X			
FL	√	√	√	√	√	√
GA	X	X				
HI	X	X	X	X	X	X
ID	X	X	X	X	√	√
IL ⁺	X	X			X	X
IN	X	X	X	X	√	√
IA						
KS	X	X	X	X	X	X
KY	X	X	X	X	√	√
LA	X	X	X	X	X	X
ME	√	√	√	√	√	√
MD	X	X	X	X	X	X
MA	√	√	√	√	√	√
MI	X	X	X	X	√	√
MN	X	X	X	X	√	√
MS						
MO ⁺						
MT	X	X	X	X	X	X
NE						
NV	X	X	X	X	X	X
NH	X	X	X	X	X	X
NJ	√	√	√	√	√	√
NM						
NY	√	√	√	√	√	√
NC	X	X	X	X	X	X
ND						

Prohibited Underwriting Action						
State	Deny coverage based on:		Raise premium based on:		Exclusion rider based on:	
	Physician discusses risk reduction options	Physician recommends risk reduction options	Physician discusses risk reduction options	Physician recommends risk reduction options	Physician discusses risk reduction options	Physician recommends risk reduction options
OH	X	X	X	X	X	X
OK ⁺	X	X	X	X	X	X
OR	X	X	√	√	√	√
PA	**	**	**	**	**	**
RI	X	X	X	X	X	X
SC	X	X	X	X	X	X
SD						
TN						
TX	X	X	X	X	X	X
UT	X	X	X	X	X	X
VT	√	√	√	√	√	√
VA	X	X	X	X	X	X
WA	√	√	√	√	√	√
WV						
WI	X	X	X	X	X	X
WY	**	**	**	**	**	

Source: Statutory research by Georgetown University and responses of state insurance regulators to Georgetown survey conducted in May-June, 2006. Regulators in five states did not respond to the survey: California, Mississippi, New Mexico, New York, and Vermont. In these states, table only indicates prohibitions found in statutory language.

√ indicates prohibition found in state statute.

x indicates state regulator confirms practice is prohibited, but practice is not specified in statute.

** Regulator did not answer this question. No statutory prohibition found.

+ Additional state notes below:

Alabama prohibitions only apply to genetic information about risk of cancer.

Arizona prohibitions unless “applicant’s medical condition and history and either claims experience or actuarial projections establish that differences in claims are likely to result from the genetic condition.”

Arkansas prohibitions apply “except to the extent and in the same fashion as an insurer limits coverage or increases premiums for loss caused or contributed to by other medical conditions presenting an increased risk.”

California prohibits insurers from denying “enrollment or coverage to an individual solely due to a family history of breast cancer, or who has had one or more diagnostic procedures for breast disease but has not developed or been diagnosed with breast cancer.”

Illinois allows an insurer to “consider the results of genetic testing...if the individual voluntarily submits the results and the results are favorable to the individual.”

Missouri prohibits insurers from inquiring “to determine whether a person or blood relative of such person has taken or refused a genetic test or what the test results of any test were...” except with approval of the applicant to consider this type of information.

Oklahoma prohibitions apply “except to the extent and in the same fashion as an insurer limits coverage or increases premiums for loss caused or contributed to by other medical conditions presenting an increased risk.”

End Notes

¹ Letter to Secretary Tommy Thompson, May 3, 2001, at [Hhttp://www4.od.nih.gov/oba/sacgt/ltr_to_secDHHS5-3-01.pdf](http://www4.od.nih.gov/oba/sacgt/ltr_to_secDHHS5-3-01.pdf)H.

² See, for example, “Testimony of the HIAA on Genetic Testing,” before the Senate Committee on Labor and Human Resources, May 21, 1998. See also “Testimony of John Rowe, M.D., Chairman and CEO, Aetna Inc.,” before the House Judiciary Subcommittee on the Constitution, September 12, 2002.

³ As cited in “Genetic testing: consumers fear it will be used to deny coverage and raise premiums” *Risk and Insurance*, April 14, 2003.

⁴ <http://www.myriadtests.com/provider/mutprev.htm>

⁵ U.S. Bureau of the Census and Bureau of Labor Statistics, 2006 Current Population Survey Annual Social and Economic Supplement.

⁶ Duchon, L., et.al., “Security Matters: How Instability in Health Insurance Puts U.S. Workers at Risk,” The Commonwealth Fund, December 2001.

⁷ Personal communication with Kathy Thomas and Ben Chaput, risk management consultants specializing in the individual market, January 20, 2007.

⁸ Karen Pollitz, Richard Sorian, and Kathy Thomas, “How Accessible is Individual Health Insurance for Consumers in Less-Than-Perfect Health?” Report to the Kaiser Family Foundation, June 2001.

⁹ Thomas and Chaput, personal communication, January 20, 2007.

¹⁰ National Association of Insurance Commissioners, “Accident and Health Insurance Industry 2004 Market Share Report by State and Countrywide,” © 2005, NAIC. Accessed November 30, 2006. http://www.naic.org/documents/research_stats_market_share_health_sample.pdf