

What does GINA Mean?

*A Guide to the Genetic Information
Nondiscrimination Act*

G  **NA**

**GENETIC INFORMATION
NONDISCRIMINATION ACT**

 Coalition for Genetic Fairness

Table of Contents

GINA: An Overview	3
The History of GINA	4
Why GINA?	4
The Long Road to Passage	5
GINA Victory – Finally!	5
How does GINA impact ME?	7
Title I: Genetic Nondiscrimination in Health Insurance	7
<i>What about submitting claims to my health insurance company?</i>	8
<i>What does GINA not do?</i>	8
Title II: Genetic Nondiscrimination in Employment	9
<i>Under what circumstances can an employer, employment agency, labor organization, or training program have access to my genetic information?</i>	10
<i>If an employer, employment agency, labor organization, or joint labor-management committee does possess my genetic information, what efforts must be made to ensure my information is kept confidential?</i>	10
<i>What does GINA not do?</i>	11
Examples of Genetic Discrimination	12
<i>In Health Insurance</i>	12
<i>In Employment</i>	12
For Health Insurers	13
<i>What information can insurers request in making coverage determinations for specific claims?</i>	14
For Employers	15
<i>When may an employer request or use an employee’s genetic information?</i>	15
<i>What efforts must employers make to ensure the genetic information of employees is kept confidential?</i>	16
For Clinicians and Healthcare Providers	17
For Researchers	17
For States	17
What’s Next?	18
Important GINA Definitions and Examples	19
Additional Resources	21

GINA: An Overview

GINA: An Overview

President George W. Bush signed the Genetic Information Nondiscrimination Act (GINA) into law on May 21, 2008. We continue to celebrate this monumental event as the culmination of thirteen years of dedication and perseverance from the health community, led by the Coalition for Genetic Fairness, and many Congressional offices.

Senator Ted Kennedy applauded GINA as “the first civil rights bill of the new century of the life sciences”. GINA protects individuals from genetic information discrimination in health insurance and employment. **The health insurance provisions of the bill, Title I, will take effect 12 months after the date of signing, on May 21, 2009. The protections in employment, Title II, will take effect 18 months after the date of signing, on November 21, 2009.** These protections will apply to residents of all 50 US States and territories.

It is believed that GINA will not only protect individuals from genetic discrimination, but will also begin to ease fear that employers or insurers would discriminate against individuals based upon genetic information. Because of this fear, some individuals have decided not to be tested or use genetic services as tools to manage health. Clinicians have had to discuss the potential for discrimination with their patients. Researchers have experienced decreased enrollment in clinical trials, due in part to participant concerns regarding genetic discrimination when research involves genetic testing.

When GINA takes effect in November 2009, every American will be protected against genetic discrimination in both health insurance and employment.

The History of GINA

Why GINA?

Genetics continues to transform our understanding of human health. Family health history helps us to understand the hereditary basis of disease. Genetic research has contributed to our knowledge of the occurrence and progression of disease, and can measure the effectiveness of medications and therapies. This research has resulted in advances in genetic technologies and services. A sign of these advances is the number of genetic tests. Since 1995, the number of genetic tests increased from a handful to over one thousand. In the past, genetic tests were available for rare diseases, but now genetic and genomic tests are developed for common diseases.

The benefits of integrating genetic information into health management are tremendous. It enables individuals and families to make proactive and informed decisions. Knowledge about one's genes can be invaluable to the delivery of healthcare services. However, that knowledge is also susceptible to misuse. Because no one is exempt from this harm—each of us carries a number of mutated genes—genetic discrimination is a potential concern for everyone.

Federal nondiscrimination legislation was proposed as a solution to both actual cases of genetic discrimination and to prevent fears of genetic discrimination, which reduced participation in testing and clinical trials. On the state level, legislatures responded to concerns by providing various levels of protection. Unfortunately, the patchwork of state laws left some individuals vulnerable. Individuals realized the privacy protections afforded by HIPAA did not prohibit insurers in the individual market from requiring genetic testing or from denying coverage based on genetic information.

The Genetic Information Nondiscrimination Act (GINA) provides a federal floor for protections. The legislation comes at a time when healthcare costs are rising, and individuals continue to express concerns that health insurers and employers, looking for ways to save money, will use genetic information as a tool to cut costs. **When GINA takes full effect in November 2009, all Americans will be free to use genetic information in health management.**

The Long Road to Passage

Genetic nondiscrimination legislation was first introduced in the House of Representatives in 1995 by Representative Louise Slaughter (D-NY), during the 104th Congress. In 1996, Sen. Olympia Snowe (R-ME) introduced similar legislation in the Senate. Both bills specifically addressed discrimination in health insurance. Neither bill passed in the 104th Congress. Similar legislation was introduced in both chambers of Congress (the US Senate and the US House of Representatives) in the 105th and 106th Congresses, but did not pass either chamber.

In 1997, a number of organizations, including Alpha-1 Association, Genetic Alliance, Hadassah, National Partnership for Women & Families, National Society of Genetic Counselors, and the National Workrights Institute, founded the Coalition for Genetic Fairness (CGF). CGF's objective was to educate the public and Congress about genetic discrimination, so that introduced genetic nondiscrimination legislation could be seriously considered. In 2005, the CGF expanded to include industry and employers. Since its founding through the day genetic information nondiscrimination legislation passed, the Coalition united hundreds of organizations and thousands of individuals as one voice against genetic discrimination.

In the 107th Congress, Rep. Slaughter introduced the Genetic Nondiscrimination in Health Insurance and Employment Act in the House of Representatives in 2001, and in 2002, Sen. Snowe introduced the Genetic Information Nondiscrimination Act (GINA) in the Senate. Both bills addressed discrimination in health insurance and employment decisions. Neither bill passed.

Similar legislation was introduced once again in the 108th Congress. In the House of Representatives, the bill (H.R. 1910) was introduced by Rep. Slaughter and gained 242 cosponsors. In the Senate, the bill (S. 1053) was introduced by Sen. Snowe and gained 23 cosponsors. The Senate bill passed 95-0, however the House bill did not pass.

In the 109th Congress, Rep. Judy Biggert (R-IL) introduced the bill (H.R.1227) in the House of Representatives. It gained 244 cosponsors, but again did not pass. In the Senate, Sen. Snowe introduced the bill (S.306), which gained 23 cosponsors. The bill passed in the Senate 98-0.

GINA Victory – Finally!

GINA saw a great deal of action in the 110th Congress. Introduced immediately in the House and the Senate, the bill began to move. The House brought the Genetic Information Nondiscrimination Act (H.R. 493) through the three committees of jurisdiction (Education and Labor, Energy and Commerce, and Ways and Means) and succeeded in passing it in all subcommittees and committees. It was a momentous occasion for the Congress and the CGF

when, on DNA Day (April 25, 2007), GINA finally passed the House, 414 - 1. It took almost another year to have the bill (S. 358) pass in the Senate, 95-0, on April 24, 2008.

On May 21, 2008, President George W. Bush signed GINA into law (Public Law 110-233). It was an historic occasion, and Francis Collins, Director of the National Human Genome Research Institute (NHGRI), Louise Slaughter (D-NY), long time champion of the bill, Judy Biggert (R-IL), Republican catalyst for the action in the last several years, were present at the signing. The CGF honored them and others in a victory party on Friday, July 11, 2008. Dr. Francis Collins led the guests in a celebratory song, "G-I-N-A", which he wrote for the occasion.

How does GINA impact ME?

Title I: Genetic Nondiscrimination in Health Insurance

The following health insurance protections take effect on **May 21, 2009**.

GINA covers genetic information of an individual and the genetic information of family members (for example, in determining family health history of disease). GINA does not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed.

The Genetic Information Nondiscrimination Act (GINA) outlines unlawful practices for health insurers in the use of genetic information.

More specifically, GINA strictly prohibits the following:

- Health insurers may not require individuals to provide their genetic information or the genetic information of a family member to the insurer for eligibility, coverage, underwriting, or premium-setting decisions. However, a health insurer may request that an individual provide genetic information if coverage of a particular claim may be appropriate only if there is a known genetic risk. For additional information, please read the Q&A portion below, entitled “What about submitting claims to my health insurance company?”;
- Health insurers may not use genetic information either collected with intent, or incidentally, to make enrollment or coverage decisions;
- Health insurers may not request or require that an individual or an individual's family member undergo a genetic test; and
- In the Medicare supplemental policy and individual health insurance markets, genetic information cannot be used as a preexisting condition.

Research exception: For joint research activities conducted by health insurers in collaboration with external research entities, a health insurer in either the group or individual market may request, but not require, in writing that an individual undergo a genetic test. **The individual may voluntarily choose to undergo such genetic testing, but non-compliance will not have a negative effect on the premium or enrollment status of the individual. Genetic information may only be used for research and not for underwriting purposes.**

What about submitting claims to my health insurance company?

With regard to making coverage determinations for a specific claim, the insurer could require genetic information. For example, the insurer may request information about an individual's BRCA status to determine coverage for prophylactic mastectomy. The insurer may request only the minimum amount of information necessary for decision-making. If an individual would not like to provide genetic information to their health insurer about such a claim, the individual can elect to pay for the test or treatment out-of-pocket.

What does GINA *not* do?

- **The protections of GINA do not include protections from genetic discrimination in life, disability, or long-term-care insurance.**
- The health insurance provisions of GINA do not apply to members of the US military, to veterans obtaining healthcare through the Veteran's Administration, or to the Indian Health Service. Furthermore, GINA does not apply to federal employees obtaining healthcare through the Federal Employees Health Benefits Plans.
- The health insurance provisions of GINA do not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed. However, GINA does protect information about manifested disease in an individual's family members (for example, their family history of disease).
- GINA does not restrict genetic services, the practice of medicine, or the authority of healthcare professionals, whether or not they are affiliated with a health plan or issuer or an employer. Clinicians and healthcare providers can recommend that an individual or an individual's family member undergo a genetic test for the purposes of that individual's medical benefit.
- GINA provides a baseline for protection against genetic discrimination for all Americans. GINA does not preempt state law; therefore if a state's genetic discrimination law provides more extensive protections than GINA, GINA does not change it. However, there is no provision within GINA that defines the strength of a law as based upon the scope of the law or the penalties associated with the law. The regulations for enforcing GINA are currently being drafted, which will clarify this definition.

Title II: Genetic Nondiscrimination in Employment

The following protections in employment settings take effect on November 21, 2009.

GINA covers genetic information of an individual and the genetic information of family members (for example, in determining family health history of disease). GINA does not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed.

Title II of the Genetic Information Nondiscrimination Act (GINA) outlines unlawful activities for an employer, employment agency, labor organization, or training program in the use of genetic information.

More specifically, GINA strictly prohibits the following:

- An employer may not use genetic information in making decisions regarding hiring, promotion, terms or conditions, privileges of employment, compensation, or termination.
- An employer, employment agency, labor organization, or training program may not limit, segregate, or classify an employee or member, or deprive that employee or member of employment opportunities, on the basis of genetic information.
- An employer, employment agency, labor organization, or training program may not request, require, or purchase genetic information of the individual or a family member of the individual except in rare cases. Please refer to the next section.
- An employment agency, labor organization, or training program may not fail or refuse to refer an individual for employment on the basis of genetic information, nor may the agency, labor organization, or training program attempt to cause an employer to discriminate against an individual on the basis of genetic information.
- An employer, labor organization, or joint labor-management committee may not use genetic information in making decisions regarding admission to or employment in any program for apprenticeship or training and retraining, including on-the-job training.
- A labor organization may not exclude or expel from membership, or otherwise discriminate against, an individual because of genetic information.

Under what circumstances can an employer, employment agency, labor organization, or training program have access to my genetic information?

- When the information is inadvertently provided as part of the individual's medical history or the medical history of a family member;
- When the information is publicly available (although not when the information is contained in medical databases or court records);
- When the employer has obtained the individual's written authorization as part of an employer-sponsored genetic monitoring program of the biological effects of toxic substances in the workplace. This is only permissible if Federal or State law requires such a monitoring program. In such cases, only the healthcare professional and the employee can know of the individual and identifiable genetic information. The employee must be informed of their individual monitoring results, but the employer can only have access to the collective genetic information of the entire group of employees, without identifying information;
- When the employer offers health or genetic services, including services offered as part of a wellness program, and with the individual's written authorization. In such cases, only the healthcare professional or board certified genetic counselor involved in providing the services may know of individually identifiable genetic information. Again, the employer may know only of the collective genetic information of the entire group of employees, without identifying information; and
- Where the employer operates as a law enforcement entity and requires the individual's DNA for quality control purposes in the forensic lab or human remains identification settings. The information may not be used for any determinations of the terms of employment.

If an employer, employment agency, labor organization, or joint labor-management committee does possess my genetic information, what efforts must be made to ensure my information is kept confidential?

Any genetic information that an employer, employment agency, labor organization, or joint labor-management committee possess about an individual must be treated as the confidential medical record of the individual and must be maintained in separate forms and in separate files. An individual's genetic information may not be disclosed except at the individual's written request or in response to a court order. However, in order to maintain compliance with existing laws, an employer, employment agency, labor organization, or joint labor-management

committee may provide an individual's genetic information to the Federal, State, or local authorities.

What does GINA *not* do?

- The employment provisions of GINA apply to those employers covered under the Americans with Disabilities Act (ADA) and Title VII of the Civil Rights Act of 1964; therefore it does not cover employers with fewer than 15 employees. Furthermore, GINA does not apply to members of the US military.
- The employment provisions of GINA do not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed. However, GINA does protect information about manifested disease in an individual's family members (for example, their family history of disease).
- The employment provisions of GINA do not interfere with an employee's ability to qualify for family or medical leave under state or federal Family and Medical Leave laws, nor to participate in an employer-sponsored wellness program or other genetic services offered by an employer. Furthermore, GINA does not interfere with an employer's ability to offer a safe and healthy work environment through federal or state required genetic monitoring of the biological effects on employees of toxic substances in the workplace.
- GINA provides a baseline for protection against genetic discrimination for all Americans. GINA does not preempt state law; therefore if a state's genetic discrimination law provides more extensive protections than GINA, GINA does not change it. However, there is no provision within GINA that defines the strength of a law as based upon the scope of the law or the penalties associated with the law. The regulations for enforcing GINA are currently being drafted, which will clarify this definition.

Examples of Genetic Discrimination

The following examples are not comprehensive but have been adapted from real examples of genetic discrimination from the Coalition for Genetic Fairness resource, in partnership with the National Partnership for Women & Families, entitled **“Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People.”**

In Health Insurance

- 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.
- Last year, Jonathon’s mother April was diagnosed with colon cancer. Because April’s aunt died of colon cancer, and her sister was undergoing chemotherapy for the cancer, April decided to undergo genetic testing to determine if the cancer could be hereditary. She tested positive for a mutation in one of four genes regulating the replication of DNA in her cells, also known as Lynch syndrome. Last month, Jonathon’s health insurance costs increased dramatically in response to the genetic test results of his mother.

In Employment

- 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.
- 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 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 soon after his employer began disciplinary proceedings to fire him.

For Health Insurers

The following protections in health insurance take effect on May 21, 2009.

GINA covers genetic information of an individual and the genetic information of family members (for example, in determining family health history of disease). GINA does not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed.

GINA outlines the following activities as unlawful insurance practices and discriminatory on the basis of genetic information:

- The requirement that individuals provide genetic information or the genetic information of a family member in determining eligibility, coverage, underwriting, or premium-setting decisions, in the group, Medicare supplemental policy, or individual health insurance markets. However, a health insurer may request that an individual provide genetic information if coverage of a particular claim may be appropriate only if there is a known genetic risk. For additional information, please read the Q&A portion below, entitled “What information can insurers request in making coverage determinations for specific claims?”;
- The use genetic information either collected with intent, or incidentally, to make enrollment or coverage decisions;
- The request or requirement that an individual or an individual's family member undergo a genetic test; and;
- The use of genetic information as a preexisting condition in the Medicare supplemental policy and individual health insurance markets.

Research exception: For joint research activities conducted in collaboration with external research entities, a health insurer in either the group or individual market may request, but not require, in writing that an individual undergo a genetic test. **The compliance by the individual with such a request is voluntary, and noncompliance shall not have a negative effect on the premium or enrollment status of the individual. Genetic information may only be used for research and not for underwriting purposes.**

What information can insurers request in making coverage determinations for specific claims?

An insurer can require genetic information to make coverage determinations for a specific claim. For example, the insurer may request information about an individual's BRCA status to determine coverage for prophylactic mastectomy. The insurer may request only the minimum amount of information necessary for decision-making. An individual can elect not to submit genetic information to the insurer about such a claim, and pay for the treatment, test, or service out-of-pocket.

For Employers

The following provisions in employment take effect on November 21, 2009.

GINA covers genetic information of an individual and the genetic information of family members (for example, in determining family health history of disease). GINA does not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed.

GINA outlines the following activities as unlawful employment practices and discriminatory on the basis of genetic information:

- The use of genetic information in making decisions regarding hiring, promotion, terms or conditions, privileges of employment, compensation, or termination.
- Limiting, segregating, or classifying an employee, or depriving that employee of employment opportunities, on the basis of genetic information.
- The request, requirement, or purchase of genetic information of the individual or a family member of the individual except in rare cases, as outlined in the drop-down section below.
- The use of genetic information in making decisions regarding admission to or employment in any program for apprenticeship or training and retraining, including on-the-job training.

Furthermore, employers should be aware that it is unlawful for an employment agency, labor organization, or training program to fail or refuse to refer an individual for employment on the basis of genetic information, nor may the agency or labor organization attempt to cause an employer to discriminate against an individual on the basis of genetic information.

When may an employer request or use an employee's genetic information?

- When the information is inadvertently provided as part of the individual's medical history or the medical history of a family member;
- When the information is publicly available (although not when the information is contained in medical databases or court records);

- When the employer has obtained the individual's written authorization as part of an employer-sponsored genetic monitoring program of the biological effects of toxic substances in the workplace. This is only permissible if Federal or State law requires such a monitoring program. In such cases, only the healthcare professional and the employee can know of the individual and identifiable genetic information. The employee must be informed of their individual monitoring results, but the employer can only have access to the collective genetic information of the entire group of employees, without identifying information;
- When the employer offers health or genetic services, including services offered as part of a wellness program, and with the individual's written authorization. In such cases, only the healthcare professional or board certified genetic counselor involved in providing the services may know of individually identifiable genetic information. Again, the employer may know only of the collective genetic information of the entire group of employees, without identifying information; and
- Where the employer operates as a law enforcement entity and requires the individual's DNA for quality control purposes in the forensic lab or human remains identification settings. The information may not be used for any determinations of the terms of employment.

What efforts must employers make to ensure the genetic information of employees is kept confidential?

Any genetic information an employer possesses about an individual must be treated as the confidential medical record of the individual and must be maintained in separate forms and in separate files. An individual's genetic information may not be disclosed except at the individual's written request or in response to a court order. However, in order to maintain compliance with existing laws, an employer may provide an individual's genetic information to the Federal, State, or local authorities.

The provisions of GINA have impacts at various levels of the employment sector, especially in the human resources division. Businesses and organizations need to prepare for the impact of GINA on their human resource practices.

For Clinicians and Healthcare Providers

GINA does not restrict genetic services, the practice of medicine, or the authority of healthcare professionals, whether or not they may be affiliated with a health plan issuer or an employer. Clinicians and healthcare providers can recommend that an individual or an individual's family member undergoes a genetic test for the purposes of that individual's medical benefit.

For Researchers

The research community will benefit from increased enrollment in clinical trials and research activities due to the protections against genetic discrimination as afforded by GINA. In the informed consent process, when discussing the potential risks associated with a particular research activity or study, researchers should prepare to include information about GINA or resources for participants to access to obtain additional information about GINA **once GINA becomes active**. The health insurance provisions of the bill will take effect 12 months after the date of signing, on May 21, 2009. The protections in employment will take effect 18 months after the date of signing, on November 21, 2009.

For States

The Genetic Information Nondiscrimination Act (GINA) provides a baseline for protection against genetic discrimination for all Americans. However, GINA does not preempt state anti-discrimination law that provides more extensive protections than GINA, either in health insurance or employment. To determine compliance with both state and federal law, states will need to compare GINA to the current state laws in place and be sure to comply with the highest level of protection provided by the legislation.

What's Next?

The next step: In order to realize GINA's potential, the health community, led by the Coalition for Genetic Fairness, will raise awareness of GINA, what it means, and how it will impact not only health insurance and employment, but healthcare delivery, research, and emerging technologies. We will encourage dialogue, and examine challenges and opportunities.

The Coalition for Genetic Fairness will convene the space for this dialogue—space that is open and where all perspectives are represented. Through this, we will inform the regulatory process, address the needs of stakeholders, and create and disseminate a variety of educational materials and resources.

What's going on now? The regulatory process for GINA has already begun: On October 10, 2008, the agencies charged with writing the regulations for GINA's implementation issued a Request for Information (RFI) in the Federal Register. The CGF will draft comments with the help and input of the health community. Visit the **Take Action** page of the CGF website at <http://www.geneticfairness.org/action.html> and learn how you can inform GINA's implementation.

Would you or your organization like to become involved in the CGF's initiatives, but are not yet a member? Visit <http://www.geneticfairness.org> or contact Andria Cornell at acornell@geneticalliance.org for more information and to learn how you can ensure the value of GINA is realized!

Important GINA Definitions and Examples

Genetic information: information about an individual's genetic tests or the genetic tests of the individual's family members, and the manifestation of a disease or disorder in the individual's family members. Furthermore, genetic information also includes the request or receipt of genetic services or participation in clinical research that includes genetic services, for both the individual and the individual's family members.

Information regarding an individual's sex or age is NOT protected genetic information under GINA.

Genetic test: the analysis of human DNA, RNA, chromosomes, proteins, or metabolites **that detects genotypes, mutations, or chromosomal changes.**

Under GINA, a genetic test does not include the analysis of proteins or metabolites directly related to the manifestation of a disease that could reasonably be detected by a healthcare professional with appropriate training and expertise in the field of medicine involved.

In the health insurance provisions of GINA (Title I), the definition of a genetic test **does not** include the following:

1. An analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or
2. An analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

It is important to note that the second exclusion listed above does not appear in the employment provisions of the law (Title II), therefore this exception does not apply in the workplace. In other words, it is okay for insurers to underwrite based on information that reveals information about current health status. However, employers may not use that same information to make employment decisions.¹

Examples of tests covered by GINA: tests for *BRCA1/BRCA2* (breast cancer) or *HNPCC* (colon cancer) mutations; tests for Huntington's disease mutations, carrier screening for disorders such as cystic fibrosis and fragile X syndrome, and classifications of genetic properties of an existing tumor to help determine therapy.

¹ "Project GINA: FAQs" Genetics and Public Policy Center. October 2008.
<http://www.dnapolicy.org/gina/faqs.html#general3>

Examples of tests NOT covered by GINA: routine tests such as routine blood counts, cholesterol tests, and liver-function tests.²

Genetic services: a genetic test, genetic counseling, genetic education, or participation in a research study.

Family member: a dependent or any other individual who is a first, second, third, or fourth degree relative.

Genetic monitoring: the periodic examination of employees to evaluate acquired modifications to their genetic materials, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects or control adverse environmental exposures in the workplace.

² Hudson, Kathy L., Ph.D., M.K. Holohan, J.D., and Francis S. Collins, M.D., Ph.D. "Keeping Pace with the Times—The Genetic Information Nondiscrimination Act of 2008." *New England Journal of Medicine*. 358.25 (2008): 2661-2663.

Additional Resources

Coalition for Genetic Fairness

www.geneticfairness.org

The Coalition for Genetic Fairness was founded in 1997 to address the growing concern surrounding the misuse of genetic information in health insurance and employment decisions. The founding organizations included the Alpha-1 Association, Genetic Alliance, Hadassah, National Partnership for Women & Families, National Society of Genetic Counselors, and the National Workrights Institute. The Coalition's objective was to educate the public and Congress about genetic discrimination, so introduced genetic nondiscrimination legislation could be seriously considered. Initially, the Coalition consisted of civil rights, disease-specific, and healthcare organizations, but in 2005 the CGF expanded to include industry groups and employers. Since its founding through the signing of the Genetic Information Nondiscrimination Act into law on May 21, 2008, the CGF united more than 500 hundred organizations and thousands of individuals as one voice against genetic discrimination.

With GINA's passage, the Coalition for Genetic Fairness will bring together the health community to play a crucial role in the drafting of the regulations for GINA's enforcement, which began in October 2008. The Coalition will educate the public and raise awareness of the legislation, what it means, and how it will impact not only health insurance and employment, but healthcare delivery, research, and emerging technologies.

Genetics and Public Policy Center

www.dnapolicy.org

The tremendous success of the Human Genome Project has laid the foundation for a true revolution in public health, promising improved diagnosis, more effective medicines, and individually tailored healthcare. The Genetics and Public Policy Center was created in 2002 at Johns Hopkins University by Pew Charitable Trusts to help policymakers, the press, and the public understand and respond to the challenges and opportunities of genetic medicine and its potential to transform global public health.

In July 2008, the Genetics and Public Policy Center announced the launch of a new website dedicated to providing information about GINA to a variety of audiences, as well as updates on the pending regulations. The resource also includes a section-by-section review of the legislation's language and a very useful FAQ. To view the new resource, entitled "Project GINA", visit <http://www.dnapolicy.org/gina>.

National Council of State Legislatures

www.ncsl.org

The National Conference of State Legislatures was founded in 1975 with the conviction that legislative service is one of democracy's worthiest pursuits. NCSL is a bipartisan organization that serves the legislators and staffs of the nation's 50 states, its commonwealths and territories. NCSL provides research, technical assistance and opportunities for policymakers to exchange ideas on the most pressing state issues. NCSL is an effective and respected advocate for the interests of state governments before Congress and federal agencies.

Included among the resources of the National Council of State Legislatures is a website outlining genetics laws and legislative activity. Individuals may choose a subject matter of interest and view a state-by-state chart of the genetics legislation in their state. This resource can be accessed by visiting <http://www.ncsl.org/programs/health/genetics/charts.htm>.

National Human Genome Research Institute (NHGRI), National Institutes of Health

www.genome.gov

The National Human Genome Research Institute (NHGRI) led the National Institutes of Health's (NIH) contribution to the International Human Genome Project, which had as its primary goal the sequencing of the human genome. This project was successfully completed in April 2003. Now, the NHGRI's mission has expanded to encompass a broad range of studies aimed at understanding the structure and function of the human genome and its role in health and disease. To that end NHGRI supports the development of resources and technology that will accelerate genome research and its application to human health. A critical part of the NHGRI mission continues to be the study of the ethical, legal and social implications (ELSI) of genome research. NHGRI also supports the training of investigators and the dissemination of genome information to the public and to health professionals.

To access information on the NHGRI website regarding genetic discrimination and GINA, please visit <http://www.genome.gov/10002077>.

Additional Information

Genetic Alliance YouTube Channel

www.youtube.com/user/geneticalliance

Genetic Counseling and Testing in Families with Hereditary Nonpolyposis Colorectal Cancer

Hadley D, Jenkins J, Dimond E, et al.

Archives of Internal Medicine

March 2003

Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People

National Partnership for Women and Families, on behalf of the Coalition for Genetic Fairness.

July 2004

Keeping Pace with the Times—The Genetic Information Nondiscrimination Act of 2008

Kathy L. Hudson, Ph.D., M.K. Holohan, J.D., and Francis S. Collins, M.D., Ph.D.

New England Journal of Medicine

June 19, 2008

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS)

Fifth Meeting, October 18-19, 2004

During the Fifth Meeting of the SACGHS, the public, healthcare providers, and additional stakeholders presented their perspectives on genetic discrimination and how the issue impacts them and their families, work, and communities, as well as the fields of research and healthcare in general.