

What does GINA Mean?

*A Guide to the Genetic Information
Nondiscrimination Act*

G  **NA**

**GENETIC INFORMATION
NONDISCRIMINATION ACT**

Coalition for Genetic Fairness

The logo for the Coalition for Genetic Fairness features the text "Coalition for Genetic Fairness" in a blue, sans-serif font. The text is centered and flanked by two symmetrical, upward-curving arcs of small, dark green dots. Each dot is connected to the text by a thin, vertical line, creating a stylized, molecular or genetic structure.

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GINA: An Overview

President 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 entire genetics community, led by the Coalition for Genetic Fairness, and more than 500 Congressional offices on Capitol Hill.

Before GINA, many individuals forwent genetic testing services, important tools for managing health, due to fears of misuse of the information were it to be obtained by employers or health insurers; research and industry suffered from decreased enrollment in clinical trials, due in part to these fears; and clinicians had to inform patients about the potential for discrimination.

As the first major civil rights bill of the new century, GINA provides individuals with federal protections against genetic 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. All individuals residing within the 50 States and US territories benefit from these protections.

Now every American can feel safe from genetic discrimination in health insurance and employment.

The History of GINA

Why GINA?

Genetics continues to transform how we look at human health. Family health history helps us to understand the hereditary basis of disease. Furthermore, genetics research has contributed to our knowledge of the occurrence and progression of disease and the effectiveness of medications and therapies—the resulting genetic technologies and services are now utilized in personal health management. The advances in genetic testing alone provide a model for this growth: since 1995, the number of genetic tests available has increased five-fold. While in the past, genetic tests were usually limited to rare diseases, new tests are now being developed that will allow for the identification of genetic predispositions to many common health conditions.

The benefits of integrating genetic information into health management are tremendous, and include enabling an individual to make proactive and informed decisions. Knowledge about one's genes can be invaluable to healthcare delivery. 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 and its related privacy concerns should be profoundly important to each of us.

Concerns of genetic discrimination, most strongly identified in health insurance and employment, prompted the need for federal antidiscrimination legislation. On the state level, legislatures began to respond to concerns by providing various levels of protection, however this patchwork of state laws left many individuals vulnerable. Cases of genetic discrimination in employment began to emerge in the US. In health insurance, individuals realized the privacy protections afforded by HIPAA did not prohibit insurers from requiring genetic testing or from denying coverage based on genetic information. We were all losing under the old guidelines: individuals would often forego genetic testing services, thus hindering their own access to the highest quality healthcare available. This also impacted healthcare providers, researchers, and industry. Large numbers of individuals opted out of clinical trials, and in turn slowed the translation of research into treatments and diagnostics.

The Genetic Information Nondiscrimination Act (GINA) answers concerns of genetic discrimination in health insurance and employment by providing a federal baseline for protections. The legislation comes at a time when healthcare costs remain a national dilemma, and individuals continue to express worries that health insurers and employers, looking for ways to save money, will use genetic information as a tool to cut costs. When GINA becomes fully active in November 2009, all Americans will be free to put their health concerns first.

The Long Road to Passage

Legislation regarding genetic nondiscrimination was first introduced in the House of Representatives in 1995 by Representative Louise Slaughter (D-NY). 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 that 104th Congress. Similar legislation was introduced in both chambers of Congress in the 105th and 106th Congresses, however not one of these bills made it to the President's desk.

In 2000, the Coalition for Genetic Fairness was founded with the objective to urge Congress to pass comprehensive federal legislation outlawing genetic discrimination and to educate the public about these protections. Initially, the Coalition consisted of civil rights, disease-specific, and healthcare organizations. In 2005, it was expanded to include industry groups and employers. From its founding through the day GINA passed, the Coalition united as one voice the hundreds of organizations and thousands of individuals who stood in support of genetic antidiscrimination legislation.

Sen. Olympia Snowe (R-ME) first introduced the Genetic Information Nondiscrimination Act (GINA) in 2002 during the 107th Congress. The bill addressed discrimination in both health insurance and employment decisions. The bill did not pass.

Similar legislation was introduced once again in the 108th Congress. In the House of Representatives, the bill (H.R. 1910) was introduced by Rep. Louise Slaughter (D-NY) and gained 242 cosponsors. In the Senate, the bill (S. 1053) was introduced by Sen. Olympia Snowe (R-ME) 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. Olympia Snowe (R-ME) introduced the bill (S.306) and it passed 98-0.

GINA Victory Celebration

On May 21, 2008, after passing in the US House of Representatives 414-1 and the US Senate 95-0 in the 110th Congress, President George W. Bush signed GINA into law. In celebration of this victory for every individual in the nation, the genetics community came together at the Genetic Alliance Annual Conference on Friday, July 11, 2008, to reflect upon the long journey, recognize our GINA champions, and share in the excitement for the future of genetics and health.

Guests representing a cross-section of the genetics and health communities were encouraged to dress in festive attire, which brought an air of lightness and fun to the event. The evening



began with the GINA History Video—a celebration of the historical moments, moving stories, and unwavering voices contributing to the passage of the legislation. At the conclusion of the video, Sharon Terry, President and CEO of Genetic Alliance, presented a toast in honor of the Members of the House and Senate who carved the path for GINA. She then presented a second toast to us all—we have all been touched by this significant piece of legislation.

Diverse members of the genetics and health community were then asked to say a few words about each of our Congressional heroes and their key staff members, who were presented with awards for their tireless support of GINA throughout its long journey to passage. Dr. Francis Collins, who had recently resigned from his post as Director of the National Human Genome Research Institute (NHGRI), NIH, recognized Sharon Terry for her visionary leadership and passion then led the guests in a celebratory song, “G-I-N-A”, which he wrote for the occasion. After a brief demonstration of the dance steps corresponding to the “G-I-N-A” song—an adaptation of YMCA—the musical number kicked off many hours of entertainment and delight, as the crowd danced the night away in celebration of this incredible victory for every individual in the nation.

Congratulations to us all.

How does GINA impact ME?

Title I: Genetic Nondiscrimination in Health Insurance

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;
- 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 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, the protections of GINA do not include protections from genetic discrimination in life, disability, or long-term-care insurance.**

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 request that an individual or an individual’s family member undergo a genetic test for the purposes of that individual’s medical benefit.

The health insurance provisions of GINA do not cover an individual’s manifested disease or condition—one that has already appeared. GINA protects an individual’s predictive genetic information. However, GINA does protect information about manifested disease in an individual’s family members (for example, their family history of disease).

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.

Title II: Genetic Nondiscrimination in Employment

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 union, 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, or if state or federal law requires the genetic monitoring program. In either case, only the healthcare professional and the employee can know of the individual and identifiable genetic information, and the employee must be informed of individual monitoring results. 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 they 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. Furthermore, in order to maintain compliance with existing laws, the aforementioned organizations or groups may also provide the 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 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.

Hypothetical Examples of Genetic Discrimination

The following examples have been adapted from “Genetic Discrimination.” Council for Responsible Genetics. 2001. <http://www.gene-watch.org/programs/privacy/genetic-disc-position.html>.

In Health Insurance

- Lisa’s young son has been having difficulty in school. Suspecting a learning disability, she consults her doctor. Her doctor performs a few genetic tests, and upon receipt of the results, informs Lisa that her son has fragile X syndrome, an inherited form of intellectual impairment. Not too long after visiting the doctor, her health insurance company eliminates her son’s health coverage, claiming that his disability represents a preexisting condition. Lisa searches unsuccessfully for another company that is willing to insure her son. She ultimately quits her job in order to qualify for Medicaid.
- 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

- Marissa has worked in a law firm for five years and has become very close with her colleagues. Over lunch one afternoon, she mentioned to a partner in her firm that her father died of Huntington’s disease. Marissa herself has a 50% chance of developing this genetic condition. Over the following month, Marissa began to notice her case load waning, and many of her colleagues who had been with the law firm for less time than she were receiving higher profile cases. She has received nothing but outstanding performance reviews throughout her time at the law firm, and can find no other reason aside from the lunch conversation with her colleagues that could be responsible for this sudden change.
- Paul learns through a company memo that a member of the large cardboard factory he works for was recently fired due to drug abuse on the job. The company has decided to institute mandatory drug screening of all employees. Paul willingly participated in the random drug-testing program, having no concerns about passing. He always takes his job very seriously, unlike some of his coworkers. Two months later, Paul overheard his supervisors discussing the impact the economy was having on the company. The following

month, Paul was called into his supervisor's office, where he was informed that the company had fallen on some hard times and would need to let him go. Confused as to why he would be selected among the individuals to be discharged, over the next few weeks he met with friends still working at the cardboard factory and learned of similarly confusing cases of high-performing, dedicated individuals who were let go with little reason. Paul has a genetic predisposition to a heart condition and high cholesterol, which could mean higher healthcare costs to the company, but he didn't think his employer would know that.

The above examples do not conclusively identify genetic discrimination in health insurance and employment; they represent situations in which genetic discrimination could be taking place. Individuals should consult law expertise to determine if they have a case for genetic discrimination.

For Health Insurers

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;
- 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

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,
- 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, or if state or federal law requires the genetic monitoring program. In either case, only the healthcare professional and the employee can know of the individual and identifiable genetic information, and the employee must be informed of individual monitoring results. 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. Furthermore, in order to maintain compliance with existing laws, an employer may also provide the 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 request 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 fully 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. At this point GINA will be considered fully active.

For States

The Genetic Information Nondiscrimination Act (GINA) provides a baseline for protection against genetic discrimination for all Americans. However, GINA does not preempt a 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.

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.

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.

Examples of tests NOT covered by GINA: routine tests such as routine blood counts, cholesterol tests, and liver-function tests.¹

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.

¹ 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 (CGF) was founded in 2000 to address the growing concern surrounding the misuse of genetic information in insurance and employment decisions. The Coalition's objective was to urge Congress to pass comprehensive federal legislation outlawing genetic discrimination and to educate the public about these protections. Initially, the Coalition consisted of civil rights, patient and healthcare organizations, but was expanded in 2005 to include industry groups and employers. With GINA's passage, the Coalition for Genetic Fairness 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. The Coalition will encourage dialogue and create the space to share in the excitement for the future, voice concerns, and seek solutions to those concerns.

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.

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.



U.S. Equal Employment Opportunity Commission

www.eeoc.gov

The five-member Commission makes equal employment opportunity policy and approves most litigation. The General Counsel is responsible for conducting EEOC enforcement litigation under Title VII of the Civil Rights Act of 1964 (Title VII), the Equal Pay Act (EPA), the Age Discrimination in Employment Act (ADEA), and the Americans with Disabilities Act (ADA).

U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR)

www.hhs.gov/ocr

The Department of Health and Human Services (HHS), through the Office for Civil Rights (OCR), promotes and ensures that people have equal access to and opportunity to participate in and receive services from all HHS programs without facing unlawful discrimination, and that the privacy of their health information is protected while ensuring access to care. Through prevention and elimination of unlawful discrimination and by protecting the privacy of individually identifiable health information, OCR helps HHS carry out its overall mission of improving the health and wellbeing of all people affected by its many programs.

We would like to acknowledge the members of the Coalition for Genetic Fairness for their contributions to this resource, as well as the entire genetics community—healthcare professionals, disease-specific organizations, researchers, industry partners, and individuals, families, and communities affected by genetic conditions. We worked as one for GINA’s passage, and now every individual in the nation will benefit from its protections.

The next step: In order to realize GINA’s potential, we must not stop at the legislation’s passage. We must educate each other and 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 must encourage dialogue, share in the excitement for the future, voice concerns, and seek solutions to those concerns.

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 the community, and create and disseminate a variety of educational materials and resources.

Would you or your organization like to become involved in the Coalition’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!