



Working to pass Genetic Nondiscrimination Legislation

Executive Committee

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President Bush Signs Landmark Genetic Nondiscrimination Information Act Into Law

WASHINGTON, D.C. – May 21, 2008 – The Coalition for Genetic Fairness (<http://www.geneticfairness.org/>) commends President George W. Bush for signing into law today the first civil rights legislation of the new millennium, the Genetic Information Nondiscrimination Act (GINA). GINA is the first and only federal legislation that will provide protections against discrimination based on an individual's genetic information in health insurance coverage and employment settings.

“This is a tremendous victory for every American not born with perfect genes – which means it's a victory for every single one us,” said Representative Louise Slaughter (D-NY). “Since all of us are predisposed to at least a few genetic-based disorders, we are all potential victims of genetic discrimination.”

“Today marks the beginning of a new era in health care,” continued Slaughter. “Americans can finally take advantage of the tremendous potential of genetic research without the fear that their own genetic information will be used against them.”

Just a few weeks ago, GINA received overwhelming support in both the Senate, with a unanimous vote of approval, and the House of Representatives, where the legislation was passed by a landslide vote of 414-1.

“Individuals no longer have to worry about being discriminated against on the basis of their genetic information, and with this assurance, the promise of genetic testing and disease management and prevention can be realized more fully,” stated Sharon Terry, president of the Coalition and CEO of Genetic Alliance (<http://www.geneticalliance.org/>). “We applaud our champions on the Hill who have worked tirelessly to pass this important legislation. It is now our responsibility to make sure the public knows that these new protections are in place.”

The health insurance protections offered by GINA are expected to roll out 12 months after the bill is signed, whereas the employment protections will be fully realized in 18 months.

“Now that GINA has been approved and signed into federal law by the President, American health care consumers and employees will no longer have to fear the adverse effects of being tested to determine their risk status for genetic diseases,” said Joann Boughman, Ph.D., executive vice president of the American Society of Human Genetics (<http://www.ashg.org/>) and a member of the Coalition’s executive committee. “Once this legislation has taken effect, clinicians will be able to order genetic tests for patients and their families in a manner that ensures the full realization of the advantages of personalized medicine, while also easing patients’ concerns about the risk of genetic discrimination by insurance companies and employers based on this data.”

Specifically, the legislation protects against genetic discrimination by health insurers or employers by:

- Prohibiting group health insurance plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of an individual’s genetic information. Insurance companies cannot request, require or purchase the results of genetic tests, and they are prohibited from disclosing personal genetic information.
- Prohibiting issuers of Medigap policies from adjusting pricing or conditioning eligibility on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.
- Prohibiting employers from firing, refusing to hire, or otherwise discriminating with respect to compensation, terms, conditions or privileges of employment. Employers may not request, require or purchase genetic information, and they are also prohibited from disclosing personal genetic information. Similar provisions apply to employment agencies and labor organizations.

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The Coalition for Genetic Fairness is an alliance of advocacy organizations, health professionals, and industry leaders working to educate Congressional policymakers about the importance of legal protections for genetic information and ensure passage of meaningful genetic information nondiscrimination legislation.

The Coalition for Genetic Fairness is led by: Genetic Alliance, Affymetrix, American

Academy of Pediatrics, The American Society of Human Genetics, Brown University, Hadassah, National Society of Genetic Counselors, and the National Workrights Institute.

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