



Working to pass Genetic Nondiscrimination Legislation

Executive Committee

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Genetic Alliance

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Senate Passes Historic Bill on Genetic Information Nondiscrimination

*Americans Can Take Advantage of Health Advances
without Fear of Discrimination*

Washington DC– April 24, 2008 – With overwhelming support, the Senate today passed the Genetic Information Nondiscrimination Act (GINA)(S. 358) by a vote of 95-0. With 46 sponsors, the bill is a testament to a strong bipartisan effort. The Coalition for Genetic Fairness commends the members of the Senate for its commitment to affording comprehensive protections against genetic discrimination.

The passing of GINA in the Senate propels us towards the responsible use of genetic information while protecting against discrimination with respect to health insurance and employment. A vote in the House is slated for next Wednesday, April 30th.

“We are grateful for the bipartisan efforts of our sponsors in the Senate – Senators Edward Kennedy (D—MA) and Olympia Snowe (R—ME) as well as the tremendous support of Senator Michael Enzi (R—WY). They are our champions and are making history today,” said Sharon Terry, President and CEO of Genetic Alliance and President of the Coalition. “Fears that genetic information could be misused hurts individuals, researchers, clinicians, and associated industries. Today, our fears have been addressed.”

Marla Gilson, Director of the Washington Action Office of Hadassah, said, “Just 10 years ago, only 100 genetic tests existed. Today, that number has grown to over 1,000 and everyday these tests are helping diagnose thousands of health conditions. Given the Jewish community's historical experiences with genetic issues, we worked hard to see that this bill was passed.”

The Coalition has worked for thirteen years toward the passage of legislation to eliminate the misuse of genetic information. Discrimination on the basis of genetic information had led individuals to shy away from genetic testing that could help them manage their health proactively. It also has caused many to opt out of clinical trials for fear that their genetic

information would be used against them. This lack of participation has slowed the research and development of treatments and beneficial drugs.

"We now have a huge task ahead of us," said Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University, "to ensure that doctors, researchers and the public are aware of the new protections GINA provides."

Just as the House of Representatives did when it passed GINA in April 2007 with 224 cosponsors, S.358 protects Americans from discrimination by health insurers or employers based on genetic information by:

- Prohibiting group health plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of genetic information. They cannot request, require or purchase the results of genetic tests or disclose 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 cannot request, require or purchase the results of genetic tests or disclose genetic information. Similar provisions apply to employment agencies and labor organizations.

The White House has signaled its willingness to sign GINA into law and a signing ceremony is expected shortly.

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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, American Heart Association, American Society of Human Genetics, Brown University, Hadassah, National Society of Genetic Counselors, the National Workrights Institute and the PKD Foundation.

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