



Applauds US House of Representatives for Passing Genetic Information Nondiscrimination Act

Washington – April 25, 2007 – The Genetic Information Nondiscrimination Act passed the US House of Representatives by a vote of 420-3 today. The Coalition for Genetic Fairness commended the members of the House in this historic moment – a testimony to the incredible passion and fortitude of many people.

“We are grateful for bipartisan efforts of our sponsors in the House of Representatives, Representatives Louise Slaughter, Judy Biggert, Anna Eshoo and Greg Walden. They are our champions, and are making history today,” said Sharon Terry, President and CEO of Genetic Alliance, and President of the Coalition.

“We would like to thank the U.S. House of Representatives for passage of the Genetic Information Nondiscrimination Act (H.R. 493),” said Marla Gilson, Director of the Washington Action Office of Hadassah. “Given the Jewish community’s historical experiences with genetic issues, we are working hard to see that this bill is passed.”

The Coalition has worked for twelve years toward the passage of legislation to eliminate the misuse of genetic information. Fear of misuse of genetic information causes many individuals to not avail themselves of genetic testing, information they can use to manage their health proactively. The potential for discrimination continues to grow as the number of available tests increases.

Studies have shown that fear of discrimination also causes many people to opt out of clinical trials. This lack of participation in research has a negative impact on researchers, clinicians, and industry, slowing the research and development process for targeted drugs and treatments. President Bush has shown his support and in a visit in February to NIH, said, “I really want to make it clear to the Congress that I hope they pass legislation that makes genetic discrimination illegal.” He issued an Statement of Administrative Policy supporting the bill.

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 non-discrimination legislation.

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The Coalition for Genetic Fairness is led by: Genetic Alliance, Affymetrix, American Academy of Pediatrics, American Society of Human Genetics, Hadassah, National Society of Genetic Counselors, and the National Workrights Institute. For more information, contact Sharon Terry, sterry@geneticalliance.org, 202.966.5557 x201

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