

## Coalition for Genetic Fairness Celebrates Passage of GINA, Honors GINA Champions

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**WASHINGTON, D.C.** – July 23, 2008 – The [Coalition for Genetic Fairness](#) recently celebrated the passage of the Genetic Information Nondiscrimination Act (GINA) with a dinner at the [Genetic Alliance](#) annual conference, *Transformational Leadership*. The Coalition honored those who put effort into making the bill a reality, with special awards for Representative Louise Slaughter (D-NY-28), Senator Edward M. Kennedy (D-MA), Representative Judy Biggert (R-IL-13), Senator Mike Enzi (R-WY), and Senator Olympia Snowe (R-ME), whose leadership was essential to the passing and signing of the bill.

“Being an advocate means understanding what it is to move something forward,” said Sharon Terry, president of the Coalition and CEO of Genetic Alliance. In this spirit, Representative Slaughter was honored for her invaluable part in the GINA effort. She was the first to introduce genetic nondiscrimination legislation on the House floor in 1995, saying, “We all have bad genes, even health insurance company executives.” Cindy Pellegrini, Assistant Director for Federal Affairs at the [American Academy of Pediatrics](#), compared Rep. Slaughter to Sisyphus, as she reintroduced the legislation every two years and finally sponsored the final version of GINA introduced in 2007. Pellegrini presented the Congresswoman’s award to Michelle Adams, Rep. Slaughter’s Legislative Director.

Senator Kennedy was celebrated for his determination to see GINA signed into law. His strong leadership in the Senate on what he called “the first major civil rights bill of the new century” led to a 95-0 vote this year. Derek Sholes, Government Relations Manager for the [American Heart Association](#), presented the award to David Bowen, Senate HELP Committee, who accepted on Senator Kennedy’s behalf.

All present acknowledged that it is in great part due to the tireless efforts of Representative Biggert that GINA ultimately met with success in the House. “Sometimes I thought science was hard, but it’s democracy that’s really hard,” said Joann Boughman, Executive Vice President of the [American Society of Human Genetics](#), who presented Rep. Biggert’s award to Brian Petersen, the Congresswoman’s Legislative Director. He reminded the audience, “We should not be punished for our genes; we should not be penalized for being proactive about our health and that of our families; and participation in clinical trials should not have consequences.”

Although neither Senator Enzi nor any of his representatives were able to attend the celebration, the Coalition for Genetic Fairness applauded his leadership in the GINA effort as one of the Senators to introduce the legislation on the Senate floor in 2007.

The Coalition paid tribute to Senator Snowe for her dedication: After the 1995 version of GINA did not pass, she reintroduced the bill in 2003, 2005, and again in 2007 and helped ensure that the final version passed easily and was signed into law. Bill Pewen, Senator Snowe's Senior Health Policy Advisor, quoted Margaret Thatcher – "You might have to fight the battle more than once to win" – as he accepted Senator Snowe's award from Kathy Hudson, Director of the [Genetics and Public Policy Center](#).

GINA is not only a milestone in American history, but a turning point in American civil rights.

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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 Society of Human Genetics, Brown University, Hadassah, National Society of Genetic Counselors, and the National Workrights Institute.*

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