



Working to pass Genetic Nondiscrimination Legislation

Executive Committee

Sharon F. Terry, Chair
Genetic Alliance

Cynthia Pellegrini
American Academy of Pediatrics

Derek Scholes
American Heart Association

Joann Boughman
American Society of Human Genetics

Timothy Leshan
Brown University

Marla Gilson
Hadassah

Barbara Harrison
National Society of Genetic Counselors

Jeremy Gruber
National Workrights Institute

Dan Larson
PKD Foundation

FOR IMMEDIATE RELEASE
May 1, 2008

For More Information Contact:

Sharon Terry – sterry@geneticalliance.org, 202.966.5557 x201

Alyssa Friedland – afriedland@geneticalliance.org, 202.966.5557 x212

House Passes Genetic Information Nondiscrimination Act
House Approval Brings Historic Bill One Step Closer to Signing

WASHINGTON, D.C. – May 1, 2008 – The U.S. House of Representatives passed the Genetic Information Nondiscrimination Act (GINA) today by a vote of 414-1, building on the momentum of last week’s unanimous Senate vote to approve this legislation.

The Coalition for Genetic Fairness (<http://www.geneticfairness.org/>) applauds the members of Congress for acting on this important bill. The Coalition has worked toward the passage of this legislation that aims to protect the privacy of personal genetic information and prevent it from being misused by health insurance companies and employers as a means to discriminate against individuals based on their genetic makeup.

“At long last, everyone with DNA can celebrate the passage of GINA in both chambers of Congress during the same session,” said Sharon Terry, president of the Coalition, and president and CEO of Genetic Alliance (<http://www.geneticalliance.org/>). “We are all so grateful to our champions in the House for their perseverance and dedication. We now look towards the signing of GINA into law.”

Once the bill has been officially signed into law by President George W. Bush, this legislation will be the first of its kind to prohibit employers and health insurers from discriminating against individuals on the basis of their personal genetic information.

“With the long-awaited federal passage of GINA, researchers and clinicians can now actively encourage Americans to participate in clinical trials without the fear of genetic discrimination,” said Joann Boughman, Ph.D., executive vice president of the American Society of Human Genetics (<http://www.ashg.org/>). “Furthermore, under the federal protection provided by GINA, health care practitioners will be able to recommend appropriate genetic testing and screening procedures unencumbered by the fear of discrimination based upon the results.”

On April 24, the Senate passed an identical version of the bill (S. 358) by a vote of 95-0. The White House has signaled its willingness to sign GINA into law and a signing ceremony is expected shortly.

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.

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.

###

PHOTOS AVAILABLE:

For all photo requests, please contact Alyssa Friedland at afriedland@geneticalliance.org or call 202-966-5557 (x212).

Coalition for Genetic Fairness • <http://www.geneticfairness.org/> • 4301 Connecticut Ave. NW #404, Washington, D.C. 20008 • Phone: 202.966.5557 • Fax: 202.966.8553

