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April 1, 2004

The Honorable J. Dennis Hastert
Speaker
US House of Representatives
Washington, DC 20515

Dear Speaker Hastert,

We urge you to consider and pass the Genetic Information Nondiscrimination Act [S. 1053], to prohibit discrimination on the basis of genetic information with respect to health insurance and employment. This bill was passed unanimously (95-0) in the Senate last year, is strongly supported by the President and currently sits at the desk in the House.

We believe that all genetic information, including family history, deserves strong and enforceable protections against misuse in health insurance and employment. Such safeguards will protect the rights, privacy and confidentiality of the individual and their family.

This is an exciting and hopeful time for genetic medicine.. It is imperative, however, that we, the public, can take full advantage of new medical advances that could help prevent disease before it develops. Genetic nondiscrimination legislation will reduce the likelihood of genetic information being misused in health insurance or employment decision-making. Genetic information is merely predictive information. Simply having a positive genetic test does not mean one will develop a disease -- thus this information should not be used to make decisions about insurance coverage or employment.

As biomedical research advances, genetic testing will become a critical tool in the provision of healthcare. As a result, many more people will know about their own genetic makeup, putting them at risk of genetic discrimination. These issues will affect you, your family members, neighbors and colleagues. We urgently request that you pass a genetic nondiscrimination bill that truly protects all of us from that risk now and into the future.

Thank you for all your hard work and efforts on this critical issue. We look forward to continuing to work with you to ensure that the Genetic Information Nondiscrimination Act passes and can be signed by the President this year.

Sincerely,

Sharon F. Terry, MA
President/CEO, Genetic Alliance

cc: Congressman Barton, Congressman Bilirakis, Congressman Boehner, Congressman Delay, Congressman Johnson, Congressman Ney, Congressman Wamp

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