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## Genetic Scientists Anticipate U.S. Senate Passage of the Genetic Information Nondiscrimination Act

BETHESDA, MD – April 24, 2008 – After more than a decade of discussions about the importance of establishing a federal standard barring discrimination in employment and health insurance on the basis of genetic information, the American Society of Human Genetics (ASHG) (<http://www.ashg.org/>) – the oldest and largest professional membership society for scientists devoted to the study and clinical application of human genetics research – today expressed their excitement about upon the U.S. Senate's imminent passage of the Genetic Information Nondiscrimination Act (GINA) (S.358/H.R. 493).

"With the passage of GINA, researchers and clinicians can actively encourage Americans to participate in clinical trials and appropriate genetic testing unencumbered by the fear of discrimination based upon the results of the genetic testing," said Aravinda Chakravarti, Ph.D., president of ASHG and professor of medicine, pediatrics, molecular biology and genetics at the Johns Hopkins University.

As a founding member of the Coalition for Genetic Fairness (<http://www.geneticfairness.org/>), ASHG has been active in educating U.S. Congress members and supporting the passage of GINA. ASHG has also urged all Society members to write letters of support to the bill's sponsors and join the ongoing efforts to inform Congress about the need for this important legislation. As a member of the Federation of American Societies for Experimental Biology (FASEB) (<http://www.faseb.org/>), ASHG joins with more than 70,000 other scientists who are members of the 21 societies in FASEB's network.

"ASHG is pleased that the Senate has united to assert leadership in addressing a national standard of protection for the American people against genetic discrimination," stated Joann Boughman, Ph.D., executive vice president of ASHG. "The House passed H.R. 493 by a vote of 420-3 on DNA Day in April 2007. This year, we are hopeful that the Senate's action will take place in time to celebrate the 2008 National DNA Day (<http://www.GenEdNet.org/>) on April 25, which commemorates the discovery of the structure of DNA in 1953 and the sequencing of the human genome 50 years later."

The purpose of this legislation is to protect the privacy of Americans' personal genetic information, and to prevent potential genetic discrimination in employment and health insurance decisions on the basis of an individual's genetic screening or testing results. Specifically, the new GINA statute will:

- Prohibit access to individuals' personal genetic information by insurance companies making health coverage plan enrollment decisions, and by employers making hiring decisions;
- Prohibit insurance companies from requesting that applicants for group or individual health coverage plans be subjected to genetic testing or screening, and prohibit them from discriminating against health plan applicants based on individual genetic information; and
- Prohibit employers from using genetic information to refuse employment, and prohibit them from collecting employees' personal genetic information without their explicit consent.

Although nearly 40 states have had individual forms of the legislation in place, with the federal passage of GINA the message would be unambiguous: the misuse of genetic information resulting in discrimination in employment or health insurance is against the law in all U.S. states.

About the American Society of Human Genetics

Founded in 1948, the American Society of Human Genetics (ASHG) is the primary professional membership organization for human genetics specialists worldwide. The nearly 8,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses and others involved in or with a special interest in human genetics. The society's mission is to serve research scientists, health professionals and the public by providing forums to: (1) share research results through the Annual Meeting and in *The American Journal of Human Genetics*; (2) advance genetic research by advocating for research support; (3) educate future professionals, health care providers, politicians, educators, students and the general public about all aspects of human genetics; and (4) promote genetic services and support responsible social and scientific policies. For more information about ASHG, please visit <http://www.ashg.org/>.

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For more information, or to schedule an interview with the Executive VP of ASHG or one of our other Genetics Experts, please contact the Society's Communications Manager:

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