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CONGRESS PASSES GENETIC INFORMATION NONDISCRIMINATION ACT

SHERMAN OAKS – (May 1, 2008) – A bill that would prohibit discrimination by health insurers and employers based on the information that people carry in their genes won final approval in Congress on Thursday by an overwhelming majority.

The legislation, which President Bush has indicated he will sign, speaks both to the mounting hope that genetic research may greatly improve health care and the fear of a world in which people's own DNA could be turned against them.

The Spondylitis Association of America is proud to have contributed to the effort to bring about this important legislation through its participation in the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition which has actively lobbied for the bill's passage since its inception in 1997.

"This is a most critical Bill protecting those whom we serve," says Laurie M. Savage, Executive Director of the Spondylitis Association of America. "SAA members and friends should take pride in their role in furthering the genetic protections that this legislation will bring about."

On the House floor on Thursday, Democrats and Republicans alike cited anecdotes and polls illustrating that people feel they should not be penalized because they happened to be born at higher risk for a given disease.

"People know we all have bad genes, and we are all potential victims of genetic discrimination," said Representative [Louise M. Slaughter](#), (D-NY), who first proposed the legislation. The measure passed the House on Thursday by a 414-to-1 vote, and the Senate by 95-to-0 a week earlier.

If the bill is signed into law, more people are expected to take advantage of genetic testing and to participate in genetic research.

The legislation, known as the Genetic Information Nondiscrimination Act (GINA), prohibits [health insurance](#) companies from using genetic information to deny benefits or raise premiums for individual policies. (It is already illegal to exclude individuals from a group plan because of their genetic profile.) Employers who use genetic information to make decisions about hiring, firing or compensation could be fined as much as \$300,000 for each violation.

"This clears away what in many people's mind had been a real cloud on the horizon," said Dr. Francis S. Collins, director of the National Human Genome Research Institute at the [National Institutes of Health](#). "Families with a strong history of genetic disease will have one less worry about the circumstances they find themselves in, and hooray for that."

The health insurance measure would not go into effect until a year after it becomes law, and the employment measure would take effect only after 18 months. Even then, there may be reason to be cautious. The bill may be hard to enforce, some experts say, and it does not address discrimination by long-term care insurers or life insurers.

The legislation, when signed, will fulfill the longstanding agreement among American citizens and politicians that protection from genetic discrimination should be clear and consistent. Until now, individuals' genetic information has been protected only by a largely untested patchwork of state and federal regulations. Ninety-two percent of Americans are concerned that results of a genetic test could be used in ways that are harmful to the person.

Moreover, scientists can now in good conscience tell patients and research participants that their genetic information is protected against misuse by health insurers and employers. Linking gene variants to health outcomes often requires studies involving large numbers of people, but scientists report that potential subjects are deterred by the fear that their information could be used against them by employers or insurers. In a survey of more than 4000 people conducted earlier this year, for example, the Genetics and Public Policy Center found that when considering whether or not to participate in genetic research, 93 percent of respondents said it was important that it be "illegal for insurers or employers to get my information."

Passage of GINA means that Americans will no longer have to make the trade-off between genetic privacy and appropriate health care.

About Ankylosing Spondylitis

Spondylitis is the term used to refer to a group of chronic, inflammatory diseases that generally strike young people between the ages of 17 and 35. Typically, spondylitis causes pain and stiffness and, in the most severe cases, can result in a total fusion of the spine and/or neck, leading to disability. Although spondylitis primarily affects the spine, it is not uncommon for the disease to impact the joints of the shoulders, hips, knees and feet, as well as cause inflammation of the eye. More rarely, because AS is a systemic (whole body) condition, other organs such as the heart and lungs can also become involved.

About the Spondylitis Association of America

The Spondylitis Association of America (SAA) is the only non-profit organization in the US dedicated to improving the lives of people with ankylosing spondylitis and related diseases. Established in 1983, SAA is committed to increasing awareness of spondylitis, providing information and support to patients and their families, and ultimately, working to uncover a cure for the disease.

SAA produces the most comprehensive library of spondylitis resources available in the US -- including books, videotapes, CDs, brochures and other publications; a 600-page website with interactive message boards; a quarterly news magazine, and a network of nationwide Educational Support Groups to educate and support people living with this chronic illness.

Behind every major milestone achieved in spondylitis education, research and treatment in the last 25 years, you'll find the Spondylitis Association of America.

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