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The Equal Rights Trust
is a company limited by
guarantee incorporated
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It is also a registered
charity, number 1113288.

Dimitrina Petrova
Executive Director

London, 23 May 2008

US Adopts Genetic Information Non-discrimination Act

On Wednesday 21 May 2008, United States' President George W. Bush signed into law the Genetic Information Non-discrimination Act (GINA), which seeks to prevent medical advances in DNA testing being adversely used by employers and health insurance companies against people with a genetic predisposition to health issues.

The Act provides groundbreaking protection for civil rights and has been described by US Senator Edward Kennedy, one of the leading advocates of the Bill, as 'the first major new civil rights bill of the new century.' The signing represents the culmination of cross-party Congressional efforts for over a decade to address the issue of genetic discrimination.

GINA offers protection to employees by preventing employers or potential employers from using genetic information in a number of discriminatory ways, including by refusing to employ or promote any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee (section 202 (a)(1)).

According to the National Human Genome Research Institute, public fears about genetic discrimination mean that many individuals do not participate in important biomedical research. Many patients also refuse genetic diagnostic tests that help doctors identify and treat diseases: they worry that they will lose their health insurance if it is proven that they are genetically pre-disposed to a disease.

GINA also amends a number of health insurance related laws, including the Employee Retirement Income Security Act of 1974 and the Public Health Service Act to prevent genetic discrimination in health insurance in a broad range of areas. In effect this should prevent health insurance companies from being able to use the genetic information in order to set premiums or determine enrolment eligibility when genetic tests reveal a susceptibility to health conditions such as cancer, heart disease and other long-term ailments.

Section 201 (4A) of the Act also sets out a broad definition of the term “genetic information”, which includes information about an individual’s genetic tests, information about the genetic tests of family members of such individual, and information about the manifestation of a disease or disorder in family members of such individual.

The Congressional Bill is a response to increasing advances in medical science and related research, giving people further and detailed information about hereditary risks of acquiring long-term health conditions. It received overwhelming approval in both the US Senate (95 votes to 0) and the House of Representatives (414 votes to 1). President George W. Bush said on enactment that the legislation would provide protections for millions of Americans ‘from having genetic information misused.’

To see the text of the Genetic Information Non-discrimination Act go to:

<http://www.equalrightstrust.org/ertdocumentbank/Gina.pdf>