

THE FORUM ON GENETIC EQUITY

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PRESS RELEASE

LANDMARK GENETIC PRIVACY BILL INTRODUCED ON BEACON HILL

The Forum on Genetic Equity is proud to mark the introduction of the **MASSACHUSETTS GENETIC BILL OF RIGHTS**. The legislation builds on passed efforts by the General Court in the early part of the 2000's to secure one's own genetic information and genetic material. The state action in Massachusetts is credited with being a major factor creating the political environment which made it possible for Congress to enact the Genetic Information Nondiscrimination Act (GINA) in 2008. GINA is considered by many to have been the single most important civil rights legislation adopted in this new century and makes it illegal to use a person's genetic information or genetic material as the basis to deny anyone Health Insurance coverage or Employment. The **MASSACHUSETTS GENETIC BILL OF RIGHTS** deepens and broadens individual rights by proactively working to end all forms of Genetic Profiling while safeguarding patient privacy rights.

MASSACHUSETTS GENETIC BILL OF RIGHTS ESTABLISHES:

- *that individuals have an expressed right to privacy with respect to genetic information and material*
- *that genetic information and material are as personal property*
- *that health care facilities cannot deny treatment & wellness services solely based on the discovery of a genetic marker.*
- *that genetic information and material may not be used in conveyance of life, long-term care and disability insurance*
- *that auto insurers cannot use genetic information in establishing policies and rates*
- *that genetic information cannot be used in determining credit worthiness*
- *that genetic information to genetic marker protections under the MA civil rights act*
- *that MassHealth cannot deny coverage and benefits solely on the basis of a genetic marker or condition*
- *that "genetic information" to the law establishing the duty to report known security breaches or unauthorized use of personal information and lays out penalties for such unauthorized use*
- *that genetic information to the criminal statutes punishing those who commit identity fraud*
- *that Protections for people with genetic markers in accessing program benefits under the Massachusetts workers compensation program*

Steve May, the Executive Director of the Forum on Genetic Equity applauded the bill's introduction: "Massachusetts has historically been a national leader when it comes to questions of consumer protection and human rights, it seems only right that the Commonwealth will be the place where the most significant effort to expand individual privacy protections and basic human rights to all people with a genetic condition or marker should launch. In the days and weeks to come, we expect a vigorous and dynamic conversation to ensue, and we welcome the opportunity to engage in this conversation on behalf of all Bay State residents with a genetic condition or marker and their families."

For more information about the Forum on Genetic Equity, please see its website: www.GeneticEquity.org

For more information about the Genetic Bill of Rights, a section by section analysis in addition to the bill text can be found on the Forum's website.