

Beacon Hill Byline by Mary Rogeness

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The Privacy of Your Genetic Code

A bill that has been filed for several years suddenly became a priority this legislative session when the mystery of human DNA was solved by scientists. The bill forbids insurers or employers to use genetic test results in determining the status of an insurance applicant or employee.

I have been a supporter of the bill for many years, and that support is only strengthened by the recent advances in genetics. Now that our genetic predisposition to many diseases can be foretold by examination of DNA samples, it is imperative that all of the citizens of the Commonwealth be guaranteed the privacy and the protection from discrimination offered by the bill.

Because of the proposed law, individuals who have reason to question whether they are at risk for developing or transmitting an inherited condition or disease can seek to answer that question in privacy. They need not put their livelihood or insurability to risk by taking such a responsible action.

The bill, officially titled the Genetic Privacy and Protection Act, was passed and sent to Governor Cellucci's desk for his approval on the last day of July. Lieutenant Governor Swift scheduled a formal signing ceremony to mark its passage because consumer privacy is one of her high priorities. However, one last hurdle remained before the bill could become law.

When Governor Cellucci studied the text of the bill, he discovered a serious flaw in its drafting. The genetic privacy appeared to extend to criminal suspects who are often required to provide DNA samples for evidentiary proceedings. He returned the bill to the house of representatives with an amendment that specifically exempts such defendants from its provisions.

A governor's amendment would not ordinarily be a serious impediment to passage. The legislature would vote to accept or reject it and again forward the bill to the governor. However, this is not an ordinary time in the legislative session. The house and senate are working in informal session, and any single lawmaker can halt proceedings by voicing an objection.

In order for the bill to be acted on, we now needed unanimous approval. The civil libertarians, who may object to compelling defendants to be subjected to DNA testing, the traditionalists, who resist any limitation of the use of such test results, all now had the power to stop the bill. But the general support for its passage outweighed any special interest.

The governor's amendment was studied by a legislative committee. It was replaced by language that is even more specific in stating that law enforcement must have access to genetic information. On August 17, the new bill was passed in both branches of the legislature. It is on the governor's desk. At long last, a bill-signing ceremony will formalize a new right to privacy for the people of Massachusetts.