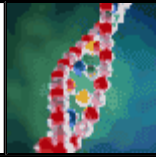


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By Sujatha Byravan and Jane Matlaw

Boston Globe

November 2, 2005

We Tend to take privacy for granted. We take it as a given that the conversations we have in our homes, what we view on television, our phone numbers, and other personal information will remain private unless we choose to share that information with others. Few of us realize that an important privacy protection is in jeopardy right here in Massachusetts.

To keep pace with recent scientific advances, the right to privacy must protect the confidentiality of our genetic makeup. Otherwise we would have no control over who has access to information that goes to

the very heart of who we are, with potentially serious consequences.

Genetic testing results can help doctors and their patients anticipate medical conditions that could arise and help them take steps to reduce

the risk. However, the benefit of obtaining genetic tests in certain situations (for example, in the case of a woman with a strong family history of breast cancer) could be offset if those same test results are turned against the individual. What happens when genetic testing results are used to determine whether someone can obtain insurance or

whether an employer will hire that individual? Or when the mere prospect of such misuse of genetic information prevents someone from

getting genetic testing in the first place?

In 2000, the Massachusetts Legislature passed legislation safeguarding

the confidentiality of genetic testing results and protecting against the misuse of genetic information. The legislation prohibits requiring genetic tests as a condition of employment or insurance, bans disclosure of genetic test results without consent, and protects against discrimination in employment and insurance based on genetic testing results.

Unfortunately, on Jan. 1, 2006, several critical provisions of this law are set to expire -- unless the Legislature chooses to act before then. The provisions set to expire protect against discrimination in life insurance coverage, disability insurance, and long-term care insurance. Without these protections on the books, insurers could require all applicants for these types of insurance to undergo genetic testing and could use the results to deny coverage or set higher rates, whether or not doing so is statistically sound in a particular instance.

The loss of privacy and the potential for discrimination is a concern for all Massachusetts residents, but especially for members of ethnic groups with a greater frequency of particular genetically influenced diseases. For example, many Jewish women of Eastern European heritage are carriers of genetic variations that have been linked to an increased risk of developing breast as well as ovarian cancer. Women in this population with additional risk factors are often urged by medical professionals to undergo genetic testing to determine whether they carry these genetic variations.

Without the protections afforded under the legislation enacted in 2000, people of all racial and ethnic backgrounds who undergo genetic testing would face potential discrimination in employment and in insurance coverage. Losing any of these protections -- including the ones that are scheduled to "sunset" on Jan. 1 -- would be a blow to many Massachusetts residents. Those who underwent genetic testing believing that the privacy of the test results was legally protected would be particularly vulnerable. And those individuals who will one day need to decide whether to take genetic tests would need to weigh that decision against the possibility that they may not be able to obtain life, disability, or long-term care insurance if they go ahead with testing.

The real-life story of "Debbie" illustrates the importance of genetic privacy. Debbie is a 51-year-old woman with a family history of breast and ovarian cancer. She was advised by a genetic counselor to consider genetic testing in order to guide her medical decision-making about preventative surgery. However, Debbie knows that parts of the genetic privacy legislation are about to sunset. For now, she is delaying important decisions regarding genetic testing and potential medical intervention until our legislators resolve this issue.

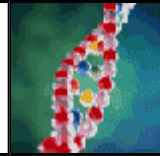
We urge the Legislature to protect the privacy of all Massachusetts residents by taking swift action to keep these important protections on the books before time runs out.

Sujatha Byravan is president of the Council for Responsible Genetics in Cambridge. Jane Matlaw is chair of the Jewish Women's Coalition on

Breast Cancer and a vice president of the Jewish Community Relations Council of Greater Boston.

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