



STATE OF MINNESOTA

Office of Governor Tim Pawlenty

130 State Capitol ♦ 75 Rev. Dr. Martin Luther King Jr. Boulevard ♦ Saint Paul, MN 55155

May 20, 2008

The Honorable Senator James Metzen
President of the Senate
322 State Capitol
75 Rev. Dr. Martin Luther King Jr. Blvd.
Saint Paul, Minnesota 55155

Dear President Metzen:

I write to inform you that Chapter 345, Senate File 3138, a bill regarding the collection and storage of genetic samples from newborns, has been vetoed. Although return of the bill to the house of origin and a veto message is not required because the Legislature has adjourned *sine die*, I wanted to share my concerns about this bill with the Legislature.

I support Minnesota's newborn screening program because it saves lives. Through this program, more than 73,000 newborns each year are screened for over 50 medical disorders. Each year, approximately 140 infants are found to have a confirmed disorder. For many of these children, early diagnosis and medical intervention prevents death or severe disability.

Under current law, the Department of Health can continue to collect newborn blood samples and conduct screening, follow-up, and test development procedures authorized by Minnesota Statutes, Section 144.123. Parents are permitted to "opt-out" of the screening process. Unless parents object, the samples are collected and screened. The ability to collect blood samples in this manner for newborn screening purposes was upheld in a recent decision by an Administrative Law Judge (ALJ). My decision to veto this bill will not change the collection or use of samples for conducting the newborn screening as currently authorized by law.

This bill would make some improvements to current law relating to the notice parents receive before genetic information is collected. I support these provisions. However, this bill would also expressly exempt the Department of

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Health from laws which require written informed consent for the Department to store and use personally identifiable genetic information for non-screening purposes. The ALJ determined that indefinite storage and additional uses of newborn blood samples require written informed consent.

I understand the Department's desire to collect and use blood samples for newborn screening purposes using an opt-out approach. However, I believe written informed consent should be obtained for the long-term storage or use of the blood samples for non-screening research.

Government handling and storage of genetic information is a serious matter. Removing the requirement for express authorization from parents regarding the long-term storage and potential future uses of genetic samples, especially when such storage and use is not related to newborn screening, is concerning.

Sincerely,

A handwritten signature in black ink, appearing to read 'T. Pawlenty', written over a horizontal line.

Tim Pawlenty
Governor

cc: Senator Lawrence J. Pogemiller, Majority Leader
Senator David Senjem, Minority Leader
Senator Ann Lynch
Representative Margaret Anderson Kelliher, Speaker of the House
Representative Marty Seifert, Minority Leader
Representative Paul Thissen
Mr. Patrick E. Flahaven, Secretary of the Senate
Mr. Al Mathiowetz, Chief Clerk of the House of Representatives
Mr. Mark Ritchie, Secretary of State