



***BREAKING NEWS ***

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CONTACT:

Deborah Hamilton, Hamilton Strategies: 215.815.7716 / 610.584.1096 or DHamilton@Hamiltonstrategies.com

Citizens' Council for Health Freedom Announces Genetic Privacy Victory

ST. PAUL, Minn. – The *Citizens' Council for Health Freedom (CCHF, www.cchfreedom.org)* announced a huge victory today with the defeat of Senator John Marty's (D-Roseville) newborn screening language.

CCHF is pleased to report that the **Data Practices Conference Committee voted not to add Sen. Marty's troubling language to the final bill**, which will become law.

Sen. Marty's language would have allowed the Minnesota Department of Health (MDH) to keep newborn screening genetic test results for seven months longer than the Minnesota Supreme Court allowed, *in spite of the fact that the court said the Department could keep them no longer than 2 years after testing to comply with a federal clinical laboratory regulation.*

The **first destruction of newborn genetic test results held by the government is set to begin on November 16, 2013**, exactly 2 years after the court ruled the Department in violation of the Minnesota genetic privacy law. However, CCHF notes that **the test results are already in the baby's medical record which is not being destroyed.**

Sen. Marty came to the committee to testify in support of his language. He and other proponents of long-term government storage of newborn genetic test results and Baby DNA, wanted a more than 6 month delay (June 1, 2014) so they could bring back legislation next session to change the law to allow long-term retention of Baby DNA and genetic test results. However, as **Rep. Peggy Scott** (R-Andover) pointed out, the Marty language would not only violate the Minnesota Supreme Court ruling, but also the long-fought and hard-negotiated agreement last year (in which CCHF participated) that changed the newborn screening law to conform to the state's high court ruling.

CCHF testified this morning that Sen. Marty's language would **set a precedent that would make the genetic privacy law's consent requirements and privacy protections for newborn citizens subject to whoever is in control of the legislature.** Subsequent legislatures could extend government storage for 2 more years, or 5 years or 18 years – effectively nullifying the law and the court ruling.

The vote to add Sen. Marty's language to the final data practice bill was called as a voice vote. However, after Chair Dzedzic said it failed, Sen. Julie Rosen (23-R) surprisingly called "division," forcing each committee member to raise their hand and declare their votes for the public to see. Rosen voted to include Sen. Marty's language, **but the House stood strong. The vote was 3-3**, which means the Marty language did not get added to the data practices bill (SF 745). Voting FOR Marty's language to circumvent the MN Supreme Court ruling, were **Senators Kari Dzedzic (60-DFL), Ron Latz (46-DFL) and Julie Rosen (23-R)**. Voting AGAINST it, and consequently for genetic privacy, were **Reps. John Lesch (66B-DFL), Steve Simon (46B-DFL) and Peggy Scott (35B-R)**.

The bill (SF 745) already gives the MDH retroactive legal protection against lawsuits from everyone else whose genetic data they've collected, stored, used, and shared without consent, without legislative authority and in violation of the genetic privacy law. It also gives MDH prospective authority to collect, store, use, and disseminate genetic information into the future without individual consent. Despite creating a state law to authorize it, this collection, storage and use of personal DNA and health data is a Fourth Amendment violation which may take a lawsuit to correct.

This is a big victory because MDH must begin to destroy newborn genetic test results from the government's data system. Destruction begins on November 16 this year - a major destruction unlike anything they've done before. The MDH began storage of newborn screening genetic tests results July 1, 1986. This destruction also sets a precedent that helps to assure that MDH will be required to destroy everything (test results and baby DNA) that was part of the Supreme Court ruling and is still on hold at MDH.

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Twila Brase is president and co-founder of the Citizens' Council for Health Freedom. She has been called one of the "100 Most Powerful People in Health Care" and one of "Minnesota's 100 Most Influential Health Care Leaders." The Council's efforts have stopped government-issued treatment directives, added informed consent requirements for access to patient data and defeated a proposed Health Insurance Exchange. Brase's daily radio commentary, Health Freedom Minute, is a 60-second radio address on pressing health care issues. She has been interviewed by CNN, Fox News, Minnesota Public Radio, NBC Nightly News, NBC's Today Show, NPR, New York Public Radio, the Associated Press, Modern Healthcare, TIME, The Wall Street Journal, The Washington Post and The Washington Times, among others.