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Destruction of Newborn Genetic Test Results Still Has NOT Begun in Minnesota

ST. PAUL, Minn.—This past Saturday was supposed to mark the first day that baby genetic test result destruction was to begin in Minnesota, marking a historic victory for the protection of private medical information and genetic privacy.

However, Twila Brase, patient advocate and co-founder of Citizens’ Council for Health Freedom (CCHF), read an email just this morning from the Minnesota Department of Health (MDH) stating that this entire process is NOT going to begin just yet. According to the email, permission has not been granted from the District Court to begin the destruction of test results for children born on or after November 16, 2011 – the day the Minnesota Supreme Court ruled MDH and the State of Minnesota in violation of the state genetic privacy law. The Attorney General’s Office filed a motion over a month ago seeking approval to begin destroying this set of test results but the judge set the motion aside and has not lifted his previous order. The email stated that the attorneys for the plaintiffs were asked to join in that motion by the Attorney General, but they have yet to respond.

Therefore, due to this red tape in the legal system, it is not known when the genetic test result destruction will commence. Brase says the law allows the health department to wait a month after November 16 if necessary. However, because of the legal entanglements, it could be several months before the law, which has already been passed, will actually take effect.

“It is disheartening, to say the least, that a procedure we and many others have worked so hard to have passed into law is held up due to one judge’s actions. More importantly, the privacy risk is still prevalent as thousands of baby genetic test results are still being stored instead of destroyed. These include nearly 30 years of test results. While the baby’s test results remain in the hands of state government, they remain the property of state government and are vulnerable to policy changes that would continue the storage forever, despite no parent consent. There was already a 2013 attempt to keep them longer than the 2012 law allows. We urge the judge to release these genetic tests results
and allow for the destruction required by law and we urge the lawyers to take similar action and to move through the lawsuit that appears to be stalling the process.”

Earlier in 2013, CCHF worked diligently to defeat Minn. Sen. John Marty’s language in a bill (SF 745) concerning newborn screening. Brase and other representatives from CCHF attended every hearing on the matter and testified against the measure as it was worded, as well as provided background on why genetic test results should be destroyed in concordance with the 2012 amendments to that newborn screening law to protect the private medical data of babies and families.

In May, lawmakers voted not to allow the troubling Marty language to be included in the bill, which, as originally written, would have allowed the Minnesota Department of Health to keep newborn screening genetic test results for seven months longer than the Minnesota Supreme Court or the 2012 law allowed. The law allowed the Department to keep the results no longer than two years, plus one additional month if necessary, after testing was performed to comply with a federal clinical laboratory regulation.

Therefore, the first destruction of newborn genetic test results held by the government was supposed to begin on Saturday, November 16, 2013—two years after the court ruled the Department in violation of the Minnesota genetic privacy law.

Sen. Marty and other proponents of long-term government storage of newborn genetic test results and baby DNA wanted a more than six-month delay, until June 1, 2014, so they could bring back legislation in 2014 to potentially change the law to allow long-term retention of baby DNA and genetic test results. But Rep. Peggy Scott stated that Marty’s language in the bill would not only violate the 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 with the November 16, 2011 Minnesota Supreme Court ruling.

Likewise, Brase testified in hearings, the troublesome language would set a precedent for continued storage 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 two additional years, five years or 18 years—nullifying the law and the court ruling.

Why is the destruction of genetic test results important? Newborn screening is genetic testing of each child within 48 hours of birth done by state government without parent consent -- although some states, like Minnesota, allow parents to opt out of the procedure. The newborn screening results contain private genetic information of the child. State storage of these results allows state government to compile a limited set of genetic information on all citizens starting at birth. A recent $25 million grant from the National Institutes of Health is focused on developing a process for genomic sequencing at birth. Government storage of the genomic sequence of a child would put the child’s entire genetic blueprint – weaknesses, strengths - in the hands of state government officials.
The legislative decision in May was a victory for genetic privacy because the state Department of Health was not allowed to extend storage beyond the 2012 amendments to the newborn screening law. They must destroy newborn genetic test results from the government’s data system in two years, or if necessary, no more than 25 months after the testing. State storage of newborn screening genetic tests results began on July 1, 1986.

Brase adds that many parents may not know that a 2003 state law gives them the freedom to refuse government newborn genetic testing altogether. Newborn genetic testing is not required by law in Minnesota, if parents express their objection in writing. Hospitals, doctors, midwives and others must advise parents that the blood or tissue samples used to perform testing, as well as the results of such testing may be retained by the Minnesota Department of Health, and that parents may decline the test. Parents may choose not to screen their baby at all, or they may opt for private newborn screening.

Twila Brase shares health care-related news with the American public in her daily, 60-second radio feature, Health Freedom Minute. Health Freedom Minute airs on the entire American Family Radio Network, with more than 150 stations nationwide, in addition to Bott Radio Network with over 80 stations nationwide. During the daily features, listeners can learn more about the agenda behind proposed health care initiatives and policies and what they can do to protect their health care choices, rights and privacy.

Brase, a public health nurse and health care freedom advocate, informs listeners of crucial health issues, such as the intrusive wellness and prevention initiatives in Obamacare, patient privacy and the need for informed consent requirements, the dangers of “evidence-based medicine” and the implications of state and federal health care reform.

Twila Brase, a public health nurse and health freedom advocate, has been called one of the “100 Most Powerful People in Health Care” and one of “Minnesota’s 100 Most Influential Health Care Leaders.” 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. Brase shares health care-related news and commentary with the American public in her daily, 60-second radio feature, Health Freedom Minute, which airs on nearly 350 stations daily, including the 150-station American Family Radio Network and the 80-station Bott Radio Network. During these daily features, listeners can learn more about the agenda behind proposed health care initiatives, the ramifications of proposed policies and actions that can be taken to protect their health care choices, rights and privacy. Health Freedom Minute is sponsored by the Citizens’ Council for Health Freedom, a patient-centered national health freedom organization based in St. Paul, Minn. CCHF supports patient and doctor freedom, medical innovation and the right of citizens to a confidential patient-doctor relationship.

For more information or to interview Twila Brase, president and co-founder of Citizens’ Council for Health Freedom, contact Deborah Hamilton, Hamilton Strategies, 215.815.7716, 610.584.1096, DHamilton@HamiltonStrategies.com.