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Legislation Will Strip Minnesota Parents of Consent for Storage and Use of Baby DNA

Citizens’ Council for Health Freedom’s Twila Brase Says Baby’s Private Genetic Identity is in Jeopardy

ST. PAUL, Minn.—There’s something expectant parents should know about the impending birth of their little ones this year. Their baby’s most precious gift—their genetic blueprint—is at risk of being used and stored forever by the Minnesota Health Department—without consent.

Twila Brase of Citizens’ Council for Health Freedom (CCHF, www.cchfreedom.org), a Minnesota-based national organization with a goal to preserve patient-centered health care and protect patient and privacy rights, is alerting Minnesota parents about a proposed modification to the newborn screening law that would allow the state to store and use indefinitely the blood spots taken at the hospital for newborn screenings. The proposed legislation would repeal the parent consent requirements in Minnesota newborn screening law allowing their baby’s DNA to be permanently filed with the government.

“As pregnant moms and expectant dads look for the safest car seats and best strollers, they should also do research into what will happen to their babies at the hospital,” Brase said. “The Minnesota legislature is planning to strip away today’s parental consent requirements for government storage and use of their baby’s DNA. Right now, the government must get consent before they can store newborn DNA or analyze it for the child’s genetic markers. If this bill passes, the child’s DNA can be used for genetic research by the state health department for decades. Newborn screening is important, but parents must have control over who has access to the baby’s blood samples and test results and what can be done with them.”

According to a special section of CCHF’s web site called ItsMyDNA.org, every state has a mandatory newborn screening program to test for serious genetic disorders and genetic traits in newborns. Within 48 hours after the birth of a baby, the heel is pricked, newborn blood is squeezed onto a card with special filter paper, and the card is sent for analysis to the state government laboratory.
or the laboratory under contract with the state department of health. At least 4 million newborn babies are tested every year in the United States.

Parents are not asked before the newborn genetic testing is done. Most states mandate the testing, and no consent is required. Some states allow parents to opt out of testing, particularly for religious reasons, however, parents are not usually informed that opting out is possible. In fact, most parents have no idea that the testing is even being done.

The proposed bill in Minnesota would repeal parental consent requirements for state government storage and use. No parent consent would be required for genetic research using the child’s DNA and data. The legislation would make it legal for the state health department to store the test results and a newborn’s genetic information indefinitely for genetic research. Parents can opt out but only if they know about the practices.

“The time of birth is very stressful,” Brase said, “and many parents don’t even realize newborn screenings are taking place during those first few days. Most don’t know it’s genetic testing. And almost no one knows it’s the government doing the testing. Many states are keeping the child’s most precious property—their genetic blueprint—to use for their own goals and initiatives. Parents can and should arrange to opt out of the testing at the hospital and instead get private testing so their child’s DNA is never in the hands of government.”

Citizens’ Council for Health Freedom also provides online forms where parents in several states, including Minnesota, Michigan, New York, South Carolina, Texas and Washington, can either complete opt-out forms or obtain more information about how to opt out in their state.

Brase, who discovered state government storage of baby DNA 11 years ago, said that current Minnesota law dictates that blood samples must be destroyed after 71 days and test results after 24 months, unless parents have consented to further storage and research. The legislation would allow the samples to be kept forever and used to delve into children’s genomes without consent.

CCHF, which is celebrating its 20th anniversary this year, was instrumental in a victory for patient freedom and the protection of private genetic data with the settlement of a Minnesota Supreme Court case last month that pitted 21 Minnesota families against the Minnesota Department of Health. The multi-year case charged the illegal and improper use of blood samples obtained under the Newborn Screening Program by the state health department. The ruling was in favor of the plaintiffs, and now those samples and test results obtained without consent must be destroyed. The new bill would undo the privacy protections gained by the ruling.

CCHF’s efforts have led to other lawsuits in Texas, as well as changes in laws and regulations in various other states, such as Oklahoma, California and New York.

Twila Brase shares health care-related news with the public in her daily, 60-second radio feature, Health Freedom Minute, which airs on more than 150 stations nationwide on the American Family Radio Network and 90-plus stations on the Bott Radio Network.
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 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 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. 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.

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