

*****NEWS RELEASE*****

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Despite New Parental Consent Provisions, Newborn Babies' DNA Still at Risk

New Law is a Step in the Right Direction, But Citizens' Council for Health Freedom Says There's Still Work to Do at State Level

ST. PAUL, Minn.—Beginning tomorrow, a newborn's DNA collected at the time of newborn screening may not be used for federally funded research unless the parents have given their express written permission, due to the Newborn Screening Saves Lives Reauthorization Act of 2014, which became law in December.

Citizens' Council for Health Freedom (CCHF, www.cchfreedom.org), a Minnesota-based national organization dedicated to preserving patient-centered health care and protecting patient and privacy rights, worked with staff members of the U.S. Senate last summer and fall to craft the parental consent requirement.

But **CCHF** says parents need to know that the blood spots taken from the heels of their babies at birth and sent to the state health department for screening can still be warehoused by the state health department without parental consent. Additionally, they can be used and shared without parental consent for research conducted without federal funds, unless a state law prohibits it.

“Consent provisions are going into effect for federal research, but unfortunately this does not protect children from any research that is done without federal dollars, including state research,” said Twila Brase, president and co-founder of CCHF. “Additionally, all states collect baby DNA, and some store it as well. Plus, four states—California, Iowa, Michigan and New York—are part of a virtual repository, which, among other things, creates a central website for researchers to locate newborn DNA ‘stored by state newborn screening programs and other resources.’ Most parents have no idea that their baby’s blood is stored, and only three states require parents to be told they can opt-out of the DNA storage and use program, while only five states let parents request the destruction of the stored bloodspots. Four states actually claim a child’s DNA as state government property.”

Thus, Brase says, there is still work to do on the state level regarding newborn DNA and protecting the genetic blueprint of newborn babies.

For example, last month, **CCHF** sent letters to about 9,700 parents of Minnesota babies born in August and September 2014 to inform them that their baby's DNA was stored without their consent by the Minnesota Department of Health after blood spots were taken for newborn genetic screening tests performed in the hospital. The letter included the official state form for parents to use to opt out of the storage and use program.

Last year, the U.S. House of Representatives passed the Newborn Screening Saves Lives Reauthorization Act of 2014 (H.R. 1281). The U.S. Senate passed the House bill, but included an amendment, crafted with the assistance of **CCHF**, that requires that parents give informed consent before their babies' DNA can be used for federally funded research. The bill was sent back to the U.S. House for re-passage, and President Obama signed it into law on December 18. The consent provisions go into effect 90 days after the enactment of the law.

Brase also added that recent studies have shown that DNA can't be anonymized, meaning that individuals can possibly be re-identified through their DNA. In a recent installment of the **CCHF Health Freedom Minute**, a weekly radio feature heard on 350 stations nationwide, Brase drew attention to an article earlier this year in Science magazine about the fact that scientists can no longer guarantee patients' privacy (["TRUST ME, I'm a Medical Researcher" by Jennifer Couzin-Frankel](#)).

"Legislators, researchers and government officials often claim you will not care if they take, store, use or share your medical data as long as they 'de-identify' it," Brase said in her Health Freedom Minute. "But this claim presumes you don't own your data once your name and certain identifiers are stripped off. It also presumes your data is public property for public use and therefore your consent is not necessary.

"But a 2007 survey of almost 2,400 people found that 'respondents were less preoccupied with whether researchers knew who they were than with knowing what was happening to their medical information,'" Brase continued. "In fact, '81 percent were not happy to have researchers parsing even so-called de-identified health data without their consent.' Exactly right."

Additionally, on its website **CCHF** links to a report titled, "Not Without My Permission," released by Public Health Genomics, which found that parents were much more likely to participate in research if asked for permission. According to the report, "if permission is obtained, 76.2% of parents were 'very or somewhat willing' to permit use of the NBS (newborn blood screening) sample for research. If permission is not obtained, only 28.2% of parents were 'very or somewhat willing.'"

CCHF first discovered state warehousing, use and sharing of newborn DNA without parental consent in 2003, and has worked the past 12 years to secure parental consent requirements at the state and federal level. **CCHF's** efforts have included alerting the public about the issue and urging lawmakers to say no to bypassing parental rights and allowing the government to have access to the genetic blueprint of America's tiniest citizens.

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For more information or to interview Twila Brase, president and co-founder of *Citizens' Council for Health Freedom*, contact Deborah Hamilton at 215-815-7716 or 610-584-1096, or Beth Harrison at 610-584-1096, Media@HamiltonStrategies.com.