

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

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Senate Passes Amendment Protecting Privacy — Measure Heads to House Today

Citizens' Council for Health Freedom's Twila Brase Says Amendment Is a Step in the Right Direction to Protect Genetic Blueprint of Babies

ST. PAUL, Minn.—The U.S. Senate last night passed an Amendment to the “Newborn Screening Saves Lives Reauthorization Act of 2014” (H.R. 1281) that will take a necessary step to protect babies’ private genetic data and ensure that parents are informed about their newborn’s screening blood spots and how they will be used.

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, led by president and co-founder Twila Brase, has been advocating on both the state and national levels for parental consent requirements for the storage and use of newborn blood samples.

“Informed consent is the strong hurdle patients and parent need to protect genetic privacy rights, and we thank all the Senators who saw fit to pass this Amendment to ensure that parents control exactly how and when their baby’s genetic information will be used for federally-funded research,” Brase said. “So many parents are unaware that after their newborn is tested for genetic disorders, many state governments retain, store and use the baby’s blood samples for research and other purposes. Some claim direct ownership of the child’s DNA.

“Now, researchers with federal grants will have to provide information to and obtain consent from parents if they want to use an infant’s dried blood spots – their DNA – for research,” she explained. “There is more that needs to be done, such as required consent for all state storage and non-federal research, but this is an important start. Parents need to be in the driver’s seat when it comes to government storage, use and sharing of their newborn’s private genetic information.”

This most recently passed Amendment to the bill, which now heads to the U.S. House of Representatives later today, adds language to the bill that will require informed consent for federally-funded newborn screening research.

Brase says it is a step in the right direction, as many parents are unaware that their baby's private genetic information is stored indefinitely and possibly used for research without their consent.

The Amendment, sponsored by Sen. Rand Paul (R.-Ky.) adds the following language to the end of the bill: "Research on newborn dried blood spots shall be considered research carried out on human subjects meeting the definition of section 46.102(f)(2) of title 45, Code of Federal Regulations, for purposes of Federally funded research conducted pursuant to the Public Health Service Act until such time as updates to the Federal Policy for the Protection of Human Subjects (the Common Rule) are promulgated pursuant to subsection (c). For purposes of this subsection, sections 46.116(c) and 46.116(d) of title 45, Code of Federal Regulations, shall not apply."

The Amendment goes on, "Not later than 6 months after the date of enactment of this Act, the Secretary of Health and Human Services shall promulgate proposed regulations related to the updating of the Federal Policy for the Protection of Human Subjects (the Common Rule), particularly with respect to informed consent. Not later than 2 years after such date of enactment, the Secretary shall promulgate final regulations based on such proposed regulations."

CCHF first discovered state warehousing and use of newborn DNA without parental consent in 2003, and has worked the past 11 years to secure parental consent requirements. Earlier this month, Brase alerted the public about the issue, urging lawmakers in this lame duck session to say no to bypassing parental rights and allowing the government to have access to the genetic blueprint of America's tiniest citizens.

*Celebrating its 20th year, **Citizens' Council for Health Freedom** is a patient-centered national health freedom organization based in St. Paul, Minn. **CCHF** exists to protect health care choices and patient privacy. **CCHF** sponsors the 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. Listeners can learn more about the agenda behind proposed health care initiatives and steps they can take to protect their health care choices, rights and privacy.*

***CCHF** president and co-founder Twila Brase, R.N., has been called one of the "100 Most Powerful People in Health Care" and one of "Minnesota's 100 Most Influential Health Care Leaders." Brase, a public health nurse, 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. She is at the forefront of informing the public of crucial health issues, such as intrusive wellness and prevention initiatives in Obamacare, patient privacy, informed consent, the dangers of "evidence-based medicine" and the implications of state and federal health care reform.*

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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, Hamilton Strategies, 215.815.7716, 610.584.1096, DHamilton@HamiltonStrategies.com.