***NEWS RELEASE***

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CONTACT:
Deborah Hamilton, Hamilton Strategies, 215.815.7716, 610.584.1096, DHamilton@HamiltonStrategies.com

CCHF to Lame Duck Congress: Baby DNA Storage Steals Private Genetic Blueprint

Citizens’ Council for Health Freedom: Don’t Allow Government to Store and Use Genetic Blueprint of America’s Citizens Without Consent

ST. PAUL, Minn.—Lame-duck Senators and Representatives currently hashing out last-minute issues before the holidays have a pressing matter before them—and it involves America’s youngest citizens.

Twila Brase, president and co-founder of 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, is alerting the public to an issue in front of lawmakers right now that puts the DNA and genetic profile of newborns at risk.

Coming up for a vote in December could be the “Newborn Screening Saves Lives Reauthorization Act of 2014” (H.R. 1281 or S. 1417), which would extend funding for five years for the program that some states use to store and use newborn DNA without parental consent for genetic research. The House passed the bill by voice vote in June, and some of the language of the bill is still being tweaked as the Senate pushes it forward. The Senate Steering Committee, however, has indicated that it wants a parental consent provision added to the bill.

“Citizens’ Council for Health Freedom strongly opposes any bill that would fund the storage, use and dissemination of newborn DNA without parental consent,” Brase said. “The current bill funds state newborn screening programs without requiring parental consent for storage, use and sharing of newborn DNA. If this lame duck Congress does move forward to pass this legislation, it must never pre-empt the ability of the states to pass something even stronger and more restrictive in terms of privacy protection for individuals—especially newborns and their parents. For example, language must be added to the bill requiring parental consent, but specifying that states can still require even more protective informed written consent for storage, use or sharing of newborn blood spots.”

In the current lame duck session of Congress, which began last month, Senators and Representatives will be on a fast-and-furious mission to clear leftover business and push through the last remaining bills before newly elected lawmakers take office in January.
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. Brase says lawmakers in this lame duck session must say no to bypassing parental rights and allowing the government to have access to the genetic blueprint of America’s tiniest citizens.

“A little-known danger of the bill is that it does not include parental consent requirements for state storage, use, analysis and sharing of newborn DNA and newborn genetic test results,” wrote Brase in a recent editorial published in the Daily Caller. “Most states conduct newborn genetic screening on every newborn. Within 48 hours after birth, a few drops of blood from the baby’s heel are squeezed onto a special card, sent to a state lab and tested for up to 50 genetic disorders. While parents support newborn screening, most parents do not know it’s a state government program or that some states store and use the newborn’s blood spots (DNA) and test results without parental consent for purposes beyond newborn screening.”

The bill under consideration by the Senate is H.R. 1281, passed by the U.S. House in June. The Senate passed its version of the bill, S. 1417, sponsored by Sen. Kay Hagen (D-N.C.), on January 29, 2014. Hagen recently lost her bid for re-election, meaning she may be even more motivated to push the bill through during the lame duck session. The bill is purportedly meant to improve health for newborns and children by allowing for detection of potentially life- and health-threatening genetic conditions.

Many parents support newborn screening, but when informed about the storage and use disagree with having their child’s genetic blueprint on file with the government or their child’s DNA used for research without their consent. Yet most parents remain unaware of this storage and use program.

Brase added that nine states currently store all or some newborn DNA indefinitely; eight states store it for more than 20 years, and four states (California, Iowa, Massachusetts and Michigan) make newborn DNA available to researchers through a “virtual repository” set up by the federal government; Indiana recently made 23 years of newborn DNA available to researchers, and Michigan requires parental consent for research using blood spots stored after May 1, 2010. Four more states (California, Maine, Utah and Washington) claim newborn DNA as state government property.

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.

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.