CCHF to Lame Duck Lawmakers:
Reject Baby DNA Storage without Parental Consent

Citizens’ Council for Health Freedom:
Don’t Allow Government to Collect and Store Genetic Blueprint of America’s Citizens

ST. PAUL, Minn.—In the current lame duck session of Congress, which began last Wednesday, 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.

But there’s an important issue that one patient and health privacy advocate wants lawmakers to pay particular attention to.

On the docket for the lame duck Senate – likely 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.

Twila Brase, president and co-founder of Citizens’ Council for Health Freedom (CCHF, www.cchfreedom.org), the Minnesota-based national organization that first discovered state warehousing and use of newborn DNA, and is dedicated to preserving patient-centered health care and protecting patient and privacy rights, 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. But most parents remain unaware of this storage and use program.

“In the name of public health, this legislation pours millions of taxpayer dollars into a state program that strips
parents of their right to have a say in who holds their child’s genetic code, strips children of their privacy and property rights, and institutionalizes national data-sharing among federal and state governments,” Brase said. “It’s one thing for newborn blood samples to be tested for a specific set of newborn genetic conditions; it’s entirely another for the government to grant itself the right to store that data and those DNA samples indefinitely, to use them for genetic research without parental knowledge or consent, to claim government ownership of citizens’ DNA at birth, and to place virtual tracking devices on children by following their health history into adolescence. Yet, this bill makes these practices reality.”

CCHF’s analysis of the newborn screen legislation uncovered multiple red flags, including:

1) **No consent requirement.** The bill requires no parental consent for long-term follow-up into adolescence, for government surveillance and access to medical records, for government data-sharing and for research using newborn data (DNA, genetic test results).

2) **Long-term surveillance.** The bill authorizes a demonstration program to evaluate the follow-up of “newborns and children at risk for heritable disorders” into adolescence. This is purportedly to assess “health and development outcomes,” but in actuality, it is government health tracking.

3) **Nationalized newborn screening.** The bill authorizes the federal coordination of state newborn screening surveillance activities, including federal standardization of data collection and reporting, as well as the use of electronic medical records for surveillance and data-sharing.

4) **Intrusive labeling, profiling and sharing.** Under the bill, federal sharing of data on newborns (including, perhaps, newborn genetic test results, newborn DNA and mother’s genetic and other data) would be shared with state birth defect and developmental disability surveillance programs.

5) **Genetic research on newborns.** The bill allows research and data-sharing using newborn data and blood specimens (newborn DNA) for conditions not yet included in the newborn screening test panel.

6) **Genetic testing of newborns for conditions not yet determined appropriate for newborn screening.** The bill authorizes pilot programs to ensure that these not-yet-approved genetic tests “are ready for nationwide implementation.”

7) **$99.5 million price tag.** The bill authorizes $99.5 million in appropriations, but does not require grant recipients to respect the genetic privacy and DNA ownership rights of newborn citizens.

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.

###

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.