

NEWS RELEASE

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House to Vote Tuesday on Newborn Blood Screening without Parental Consent

Citizens' Council for Health Freedom Urges Opposition to Bill that Grants Government Ownership of Newborn DNA

ST. PAUL, Minn.—The U.S. House of Representatives will vote on Tuesday on the Newborn Screening Saves Lives Reauthorization Act of 2014 (H.R.1281), which would extend for five years the funding program that allows states to collect and store newborn DNA without parental consent.

The bill, sponsored by Rep. Lucille Roybal-Allard (D-CA-40) is purportedly meant to improve health for newborns and children by allowing for detection of potentially life- and health-threatening genetic conditions.

But *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, says the legislation is a back-door effort to bypass parental rights, collect and store newborn DNA and expand government access to the genetic code of Americans.

“In the name of public health, this legislation continues a 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,” said CCHF co-founder and president Twila Brase. “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, and to place virtual tracking devices on every child by following their health history into adolescence. Yet, these are exactly what this bill does.”

CCHF’s analysis of the 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 followup 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 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.

The U.S. House is scheduled to vote on this legislation on **Tuesday, June 24, 2014**. **CCHF** is urging Americans to contact their Member of Congress and urge opposition to this bill as it strips parents of initial right of consent, grants default ownership of newborn genetic code to the state and empowers the government to conduct long-term surveillance of newborns into adolescence. Individuals may locate contact information for their Representative by [clicking here](#).

*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.