

\*\*\*NEWS RELEASE\*\*\*

For Immediate Release  
July 17, 2014

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## Who Has Your Baby's DNA?

### *Citizens' Council for Health Freedom Says Indiana Should Destroy Newborn DNA Stored Without Parent Consent*

**ST. PAUL, Minn.**—*Citizens' Council for Health Freedom (CCHF, [www.cchfreedom.org](http://www.cchfreedom.org))* is alerting parents in Indiana to take action to protect the genetic privacy of their newborn babies.

For 23 years, the State of Indiana has been storing blood samples and DNA of newborn children without the consent of their parents. After a media investigation and report, parents were surprised to learn that the Indiana State Department of Health is storing the blood and DNA of 2.25 million children in an undisclosed warehouse.

Following the investigation, state health officials are planning to make the blood samples available to researchers despite admitting they didn't have consent from parents to store them or use them for research.

Twila Brase, co-founder and president of *CCHF*, a Minnesota-based national organization dedicated to preserving patient-centered health care and protecting patient and privacy rights, says the blood samples should be destroyed and is encouraging parents to take action to ensure that happens.

***"It's one thing for newborn blood samples to be tested for a specific set of newborn genetic conditions," Brase said. "It's entirely another for the government to grant itself the right to use them for genetic research without parental knowledge or consent. State and federal initiatives to expand newborn screening programs have proven to be a back-door effort to bypass parental rights, store and use newborn DNA and expand government access to the genetic code of Americans."***

According to the report, Indiana, like most other states, conducts a newborn screening test on every newborn. As required by state law, a few drops of blood are taken from the heel of each baby, collected on a card and sent to the Newborn Screening Lab in Indianapolis, where researchers test the spot for more than 50 disorders.

The state, however, does not have parental consent to use the blood spots for anything else or to store them. Now, as a result of the media investigation, the state will ask parents for permission up front to

allow their newborn baby's blood to be used for research. And if they say no, their child's blood sample is no longer kept for decades.

The health department has also created [new online consent forms](#), where parents with children who were born between 1991 and 2013 can inform the state on whether they want the blood sample to be destroyed or used for research.

But the website of the Indiana State Department of Health says it is making newborn blood saved before June 1, 2013 available to researchers. It's doing so without parental consent because "no identifiable information about your baby will ever be released."

***Brase counters, "DNA is the most identifiable information. It's a step in the right direction that the Indiana Health Department is now requesting permission for research – but that doesn't help the 23 years of children whose DNA is on file with the government without their consent.***

***"There's no outreach effort, the online forms for children whose DNA has been stored the past 23 years puts the burden on the violated to stop further violation, and it's highly unlikely that the families of all 2.2 million children will see the news story," says Brase. "Most parents will remain as clueless as they were before the news story. The default position of the State should be respect for genetic privacy and the immediate destruction of the samples."***

Brase and **CCHF** have been vocal on the issue of newborn DNA for years, spearheading efforts both on the state and national levels to require parental consent before government can store and use newborn DNA. This issue continues to be one debated by parents, lawmakers, medical professionals and privacy advocates.

*Celebrating its 20<sup>th</sup> 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](mailto:DHamilton@HamiltonStrategies.com).**