

NEWS RELEASE

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The Scary Truth Behind Birth Certificates

Citizens' Council for Health Freedom Releases New Report on Newborn Data Collection; Says Birth Certificates and Newborn DNA Storage Pose Double Threat

ST. PAUL, Minn.—There's something expectant parents should know about the private, sensitive information being shared at the hospital at the time of their baby's birth. According to a new report from *Citizens' Council for Health Freedom (CCHF, www.cchffreeedom.org)*, much of the information requested for the birth certificate is intrusive and violates the family's privacy rights.

CCHF, a Minnesota-based national organization dedicated to preserving patient-centered health care and protecting patient and privacy rights, recently released its [report](#) called, "Not Just a Birth Certificate: How states use birth certificates to collect data, conduct research and warehouse electronic health information."

CCHF's president and co-founder, Twila Brase, says during the somewhat stressful time of a new baby's arrival, precious private information about these new little lives will be shared with countless others, through a seemingly harmless document—the birth certificate. And she says it's part of a larger pattern.

"Taken alone, a birth certificate seems like a harmless public document for basic information," Brase said. "But over time, states have decided to use them as a data collection tool. And much of the data that is collected has nothing to do with the legal requirements of registering the birth of a child. Unfortunately, this is just one cog in the massive wheel of data collection operated by state and federal government agencies."

The goal of the report is to educate expectant parents about state data collection that takes place when they visit a hospital to have their baby, and actions they can take to limit the collection. Much of the information collected at the time of birth, Brase added, allows the state, and possibly federal agencies, to conduct unconsented research and analysis of the family.

For the report, *CCHF* researched details from vital statistics agencies and hospitals in 28 states plus the District of Columbia about what they collect at the time of birth. Most of the data is collected on a document often called a "birth certificate worksheet." *CCHF* also reported the data elements for collection suggested by the Centers for Disease Control (CDC).

CCHF has also been instrumental in working on legislation that protects two additional aspects of infant and family privacy—newborn screening results and baby DNA.

In December, lawmakers passed the “Newborn Screening Saves Lives Reauthorization Act of 2014,” which includes an amendment pushed by CCHF that prohibits the use of newborn DNA for federally funded research unless the researchers have express written informed consent. **CCHF** has long fought for parent consent requirements, but Brase says the federal law gives states an opportunity to make their newborn DNA laws even more stringent.

The newborn screening law, for example, only stipulates that parents be informed about federally funded research, and there is still no consent required for government storage of DNA. Furthermore, Brase added, newborn blood spots will be protected under the measure beginning 90 days after the enactment—Dec. 18, 2014, when President Obama signed the law. Therefore, until March 18, newborn blood spots are still available for research without consent, and parents will not legally have to be informed about how their baby’s DNA is used.

Similarly, many parents are not fully informed about the collection of data through the birth registration process. Sometime parents are given a birth certificate worksheet that makes the collection more obvious; sometimes the data is simply collected from the medical record. Many states gather similar data, but some states collect more than other states. Some worksheets include statements about research. Others do not. Personal details unrelated to simple birth registration, but collected and submitted as part of the process, can include parents’ educational level, household income, race/ethnicity, the source of payment for the delivery, complications or infections during the pregnancy, abnormal conditions or congenital anomalies of the newborn, if the mother smoked, drank alcohol or used drugs during the pregnancy, or even if the mother exercised during pregnancy, if she felt depressed and how she felt about being pregnant (asked in New York only).

While some of these are important questions for the medical record, Brase said, the answers should not be part of the birth certificate and should not be accessible by government agencies for research and other purposes—especially when the baby’s parents are unaware of how this personal information will be used, and have not given their consent.

Brase said, “Through birth certificate data collection and the storage, use and research on newborn DNA without parental consent, we see a pattern of data mining for government research and statistical gathering. Babies are being profiled by the state from birth, and they and their families—mothers in particular—are becoming research subjects as soon as a baby is born. And the truth is, most Americans have no idea this is happening.”

For those expecting a new addition to their family in 2015, Brase suggests that parents check with their individual state health departments and the hospital where they’ll be having their baby to see what kinds of information will be collected at the time of birth. Some states, such as Brase’s home state of Minnesota, give parents the right to refuse to provide information.

“Parents need to take action to protect their family’s privacy,” she said. “Most people think the hospital is a safe place and the birth certificate process is free from harm. But hospitals and clinics have willingly or unwittingly become data collection agencies for the government. All of this private data is being collected and used by government officials without consent. The danger lies in the fact that states today have extensive data on babies, mothers and families that they should not have for purposes the family has not consented to.”

Parents can also take the following actions, which are detailed in the report:

- Request that the hospital use only basic data for the birth certificate.
- Share your birth certificate experience with your state legislator, most of whom don’t know about the government’s extensive data collection habits.
- Choose private testing for newborn (genetic) screening; more information is available at www.itsmydna.org.
- Remember that HIPAA is not a privacy rule, but rather a disclosure rule, potentially allowing 2.2 million entities, plus government agencies, to access your medical data.
- Contact hospitals, birthing centers and midwives to ask what data they send to the state.
- Tell CCHF about your birth certificate experience at info@cchfreedom.org.

For more information about **CCHF**, visit its web site at www.cchfreedom.org, its Facebook page at www.facebook.com/cchfreedom or its Twitter feed @TwilaBrase.

Citizens’ Council for Health Freedom is a patient-centered national health freedom organization based in St. Paul, Minn., that works to protect health care choices and patient privacy. CCHF sponsors the daily, 60-second radio feature, Health Freedom Minute, which airs on approximately 350 stations nationwide, including 200 on the American Family Radio Network and 100 on the Bott Radio Network. Listeners can learn more about the agenda behind 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.” A public health nurse, Brase 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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