

NEWS RELEASE

For Immediate Release

February 9, 2015

CONTACT:

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

Birth Certificates Are a Data-Collection Vehicle for the Government

Patient Advocate Says Parents Can Refuse to Give Private Information about Babies, Mothers and Families at Hospital

ST. PAUL, Minn.—The birth of a baby is a joyous time, filled with activity, questions from new parents and lots of information sharing—especially at the hospital.

But during that somewhat stressful time, precious private information about these new little lives will be shared with countless others, through a seemingly harmless document—the birth certificate.

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, recently released a [new report](#), called “Not Just a Birth Certificate: How states use birth certificates to collect data, conduct research and warehouse electronic health information.”

The goal of the report, said **CCHF** president and co-founder Twila Brase, is to educate expectant parents about state data collection that takes place when they visit a hospital to have their baby. And much of it, Brase added, allows the state, and possibly federal agencies, to conduct unconsented research and analysis with the information given and accessed at the time of birth.

“Parents think birth certificates are a harmless public document for basic information,” Brase said, “but over time, states decided to use them as a data collection tool. Much of the data has nothing to do with the legal requirements of registering the birth of the child. State agencies are simply using the birth of a baby as an opportunity to gather data on families.”

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).

When a baby is born, the worksheet is used to gather the data. Many states gather similar data, but some states collect more than other states. Some forms include statements about research. Others do not. Personal details unrelated to simple birth registration, but collected and submitted as part of the process, 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, “At a vulnerable time in their life, when parents are using the services of a trusted facility, the birth certificate becomes an opportunity to mine data from the family for government research and statistical gathering. Babies are being profiled by the state from birth, and therefore, they and their mothers in particular become involuntary research subjects as soon as they are born.”

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 stop this massive data collection,” 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.”

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

- Politely refuse to answer behavior and lifestyle questions at the doctor’s office or hospital.
- Request that the hospital use only basic data for the birth certificate.
- Share your birth experience with your state legislator, most of whom don’t know about the government’s extensive data collection habits.
- Remember that HIPAA is not a privacy rule, but rather a disclosure rule, giving 2.2 million entities, including government agencies, possible access to your medical data.
- Contact hospitals, birthing centers and midwives to ask what data they send to the state.
- Tell CCHF about your birthing experience at info@cchfreedom.org.

###

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.