

*****NEWS RELEASE*****

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Minnesota Department of Health Tries to Shut Down *CCHF*'s Informative Mailings to Parents About Use and Storage of Baby DNA

Proposed Amendment Would Make Historically Public Birth Data Private, So Citizens' Council for Health Freedom Is No Longer Able to Inform Parents of State's Secret DNA Storage and Use

ST. PAUL, Minn.—For more than a century, the contact information from state registration of births has been public in the state of Minnesota. And that information is how *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 sent nearly 10,000 letters to parents of newborns, letting them know that the state of Minnesota is storing and can use their baby's DNA for genetic research without consent.

But now, just a month after the letters were mailed, the Minnesota Department of Health is spearheading an effort to restrict access to this public data—most likely to prevent *CCHF* from sending additional letters. An amendment added to a bill would make the contact information private, effectively shutting down *CCHF*'s recent initiative to educate and inform Minnesota parents.

The Minnesota Senate Judiciary Committee, chaired by Sen. Ron Latz (D-St. Louis Park), recently accepted the amendment to the APCD (All-Payer Claims Database) bill (HF 1961) offered by Sen. Kathy Sheran (D-Mankato), chair of the health care policy committee. Despite testimony from *CCHF* president and co-founder Twila Brase opposing the amendment, the committee approved the amendment. It will now head to the Senate Finance Committee.

Brase believes the move by the Senate committee is a direct result of the successful *CCHF* mailing that educated parents about the government's storage of their baby's private genetic information. In fact, birth records are public in 47 states plus Washington, D.C. Genealogists, legislators, newspapers, businesses and life insurers are some of those who regularly use the data.

"This is an interesting amendment, in that we have just started a project to contact people using public birth certificate information about the fact that the DNA of their children is being stored," Brase testified at the March 20 hearing. "This is apparently the only way we have to let people

know about the fact that the DNA is being stored. This amendment would stop us from being able to tell the public in the state of Minnesota that their DNA is being stored by the health department and give them an opportunity to opt out.”

She added that parents are thanking **CCHF**, saying that they had no idea their child’s DNA was being stored by the State.

In 2003, **CCHF** discovered that governments at the state and federal levels were using baby DNA for research and storage without parental consent. The discovery led to two lawsuits—one in Minnesota and one in Texas—and both were successful for the parent plaintiffs.

As a result, in Minnesota, more than 1 million blood spots samples containing baby DNA were destroyed, along with the babies’ genetic test results that were stored since 1986. The DNA samples had been stored since 1997.

Responding to the Minnesota Supreme Court decisions, Minnesota added parent consent requirements to its existing genetic privacy law in 2012. But in 2014, the Minnesota Department of Health found a loophole in the law and, with assistance from the DFL-controlled legislature, used it to repeal parent consent for storage and use of newborn DNA for genetic research. Although more than 1 million blood spots have been destroyed, the Minnesota baby DNA storage and use program began again on Aug. 1, 2014. The only option for parents is to opt out, but only if they learn that their baby’s DNA is being stored. Hospitals don’t take any proactive action to inform parents about this practice.

So to inform parents of this reversal of the law, **CCHF** sent nearly 10,000 letters in mid-February to parents of babies born in August and September 2014, telling them that their baby’s DNA was stored without their consent by the Minnesota Department of Health after blood spots were taken for newborn genetic screening tests performed in the hospital.

“Apparently our trial mailing program was so successful, the Minnesota Department of Health now wants to shut it down,” Brase said.

Brase added that, according to one privacy expert - a former official from the Minnesota Department of Administration - birth information has been public virtually since Minnesota’s statehood.

“All sorts of people use this data,” Brase said, “for marketing, for genealogy, for announcing births in small newspapers. Even legislators use it to congratulate new parents. But when we used it to tell parents of the opt-out option in the law, the Department moved to eliminate all access. In essence, the state wants to shut down all access so parents will never hear that the Minnesota Health Department is warehousing and potentially using their baby’s DNA.”

CCHF has heard from many parents who were irate to learn of the health department’s DNA practices, and many more parents were thankful to learn they have the choice to opt out.

Brase added that parents *should* be concerned that their baby’s genetic blueprint is being used and stored by the government.

“A child’s DNA could even be sequenced,” she said, “meaning a baby’s genetic code could be completely detailed and mapped—and then recorded in a state government database, used and shared.”

In its letter to Minnesota parents, **CCHF** also directed them to learn more at the organization’s special Baby DNA web site: www.ItsMyDNA.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, @CCHFfreedom.

Citizens’ Council for Health Freedom is a patient-centered national health freedom organization based in St. Paul, Minn., that exists 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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For more information or to interview Twila Brase, president and co-founder of *Citizens’ Council for Health Freedom*, contact Deborah Hamilton at 215-815-7716 or 610-584-1096, or Beth Harrison at 610-584-1096, Media@HamiltonStrategies.com.