Minnesota to Resume Storing Baby DNA August 1 without Parental Consent

Citizens’ Council for Health Freedom: State Government Will Store and Research Private Genetic Info; Opt-Out Form Still Not Available

ST. PAUL, Minn.—This Friday will mark a huge step back in privacy rights for Minnesota’s tiniest residents—and the new law could have national implications.

Minnesota once asked parents for consent to have their newborn baby’s DNA stored by the state and/or used for research. But as of August 1, 2014, no consent is required. Parents must take the initiative to tell the hospital that they don’t want their baby’s blood spot used for any purpose other than newborn screening. Unfortunately, most parents won’t even know the state is storing their child’s DNA or that they need to opt-out to prevent government storage and use. Furthermore, the required opt-out form that should be available to all parents and hospitals has yet to be posted on the Minnesota Department of Health’s website. A representative said the form is at the draft stage.

Twila Brase, co-founder and president of 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 reversal of the law signed by Governor Mark Dayton on May 6, 2014 (which takes effect this Friday, August 1), should be alarming to parents and all residents as the government is taking ownership of babies’ private genetic information and using it for its own purposes and initiatives.

“Any baby born August 1 and going forward will have their DNA stored indefinitely and shared for genetic research without parental consent,” Brase said. “By this weekend, the only option for parents will be to opt-out, provided they know about the changes in the law and provided the opt-out form is available in time.”

Brase also encourages parents to keep checking the Minnesota health department web site at http://www.health.state.mn.us/ until the 2014 form is uploaded. Currently, the site lists a link to a 2012 form, which is misleading for parents because it does not take into effect the recent changes to the law.

“Anyone who reads the site today and who has a baby due in the coming weeks, won’t find accurate information,” Brase said. “Parents checking the site now would think that their baby’s blood spots
would be destroyed in 71 days. There is nothing on the site to warn of the impending long-term storage and use.”

The decision by the Minnesota legislature to eliminate parental consent requirements and begin storing newborn DNA without consent is a reversal from the hard-fought battle for patient privacy, in which CCHF and other organizations were instrumental.

In 2009, a lawsuit orchestrated by CCHF was filed. In 2011, the Minnesota Supreme Court ruled in favor of parental consent. In 2012, the legislature added consent requirements to the newborn screening law, and in January 2014, more than 1 million DNA samples were destroyed as a result of the court case, which pitted 21 Minnesota families against the Minnesota state health department.

But the 2014 state legislature ignored the court’s decision and stripped parental consent requirements out of the law. Starting on August 1, 2014, newborn DNA and genetic test results will be kept indefinitely—and perhaps used for research—even if parents did not consent. The DNA of babies born between January and July 31, 2014 will be stored for about 70 days, then destroyed. The test results of these babies will be kept for two years, then destroyed.

“What we find is that most parents have no idea their baby’s genetic information—the blueprint of who they are—is being stored and used by the government for research purposes,” Brase said. “And when they find out, most are surprised. Many are upset. Furthermore, when asked, the majority of parents are unwilling to have their child’s DNA stored and used for research without consent. We are encouraging parents who are expecting babies to take action and opt out. But we also realize that when a mom is in labor at the hospital and a dad has a lot on his mind, it’s not likely they will remember to ask for the form.

“Additionally, with just days to go before the state starts collecting and storing newborn DNA, the Minnesota Department of Health has yet to provide the opt-out form to the public. And there is no confirmation from the Department that hospital staff have even been informed or instructed on how to advise patients on where and how to access the opt-out form.”

CCHF warns that government harvesting and storage of newborn DNA is not limited to Minnesota but is a practice nationwide. In fact, only two states—Michigan and Oklahoma—currently require parental consent for research on newborn DNA. And four states make newborn DNA available in a nationwide ‘virtual repository’. Furthermore, the U.S. Senate is currently considering the Newborn Screening Saves Lives Reauthorization Act of 2014, which would provide nearly $100 million in funding for state newborn screening programs but which contains no provision for parental consent requirements.

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.