

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

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New Parent Lawsuit Exposes Stolen 'Baby DNA,' Says *Citizens' Council for Health Freedom*

*Many States Are Storing, Using and Sharing Newborn DNA
for Research Without Consent—and Most Parents Have No Idea*

ST. PAUL, Minn.—*Citizens' Council for Health Freedom (CCHF)* is applauding a [new lawsuit](#) where a group of parents are suing the state of Michigan for “stolen blood” because the Michigan BioTrust for Health stores Baby DNA for research—without parental consent.

The attorney in the case, Philip Ellison, is the father of a newborn who gathered nine other families for a federal lawsuit to sue the government for storing newborn DNA for [100 years](#) without consent. Ellison says the Michigan law authorizing storage and genetic and other research on newborn blood without parental consent ([Section 333.5431](#)) is unconstitutional and violates the Fourth and Fourteenth Amendments, he writes in the [federal court complaint](#), according to Twila Brase, co-founder and president of *CCHF*.

CCHF first began educating Americans about the use and storage of baby DNA without parental consent more than 10 years ago. In fact, *CCHF* successfully helped 21 Minnesota families win a similar lawsuit requiring all baby DNA specimens be destroyed by the state health department. Unfortunately, the legislature changed the law and storage began again without parental consent on Aug. 1, 2014.

Brase says laws and federal and state regulations impact how baby DNA is collected and used for research—without parents ever realizing it.

“Our organization uncovered state-based ‘Baby DNA Warehousing’ in 2003,” Brase said. “As a result, four parent lawsuits (one in Indiana, one in Minnesota, two in Texas) have been filed, and judges have required millions of newborn DNA blood spot cards stored by state government to be incinerated. We hope the same happens in Michigan, where approximately 5 million cards are stored. Most parents, in the fog and exhaustion of labor and delivery, do not realize that: 1) newborn screening even happens, 2) newborn screening is a state government program, 3) the blood from the newborn heel prick is sent to the state public health laboratory, and 4) many states are storing, using and sharing the DNA without parental consent, including for genetic research.”

Most states conduct genetic screening on every newborn. Within 48 hours after birth, a few drops of blood from the baby's heel are squeezed onto a special card, sent to a state lab and tested for 32 or more genetic disorders. While most parents who know about the program (many don't) support newborn screening, most do not know it's a government genetic testing program or that the newborn's dried blood spots and test results can be used and shared without parental consent for purposes beyond newborn screening.

Brase advised that these blood spots contain the private genetic makeup of the baby and should not be used, without parental consent, for research or other purposes. Therefore, **CCHF** urges parents who have a baby on the way, or who have recently welcomed a new addition, to research how their state utilizes newborn DNA, how long they store it, if they use newborn DNA for research purposes, and whether the parents can opt out of storage and research. **CCHF** invites parents to learn more at its special "Baby DNA" web page: www.ItsMyDNA.org.

Although state law does not require consent, Michigan officials added parental consent requirements for research for children born after May 1, 2010. The stored DNA of four million children born earlier can be still be used for research without parental consent. Brase noted that if lawsuits in 2009 and 2010 had not been filed as a result of **CCHF's** efforts, it's likely that everyone born in Michigan, not just those born before May 1, 2010, would be in the "no consent necessary" group. The current lawsuit may also not have gone forward, as Mr. Ellison only learned about the unconsented storage of his child's DNA because he was asked to consent to using it for research.

"Kudos to Philip Ellison for realizing his child's DNA had been stolen and for taking on the Michigan government, the government biobank, and the companies and researchers who think a child's DNA is public, not private, property," said Brase.

Learn more about the Michigan case at stolenblood.com and read the full [CCHF Commentary](#) on the lawsuit.

For more information about **CCHF**, visit www.cchffreedom.org, its [Facebook](#) page or its Twitter feed @CCHFFreedom. Also view the [media page for CCHFhere](#). For more about **CCHF's** initiative *The Wedge of Health Freedom*, visit www.JointheWedge.com, *The Wedge* [Facebook](#) page or follow *The Wedge* on Twitter @wedgeoffreedom.

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