

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

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Parents and Newborns Harmed by Unconsented State Storage of Baby DNA

*Opposing Judge's Decision, Citizens' Council for Health Freedom
Says the Harm Is in the Taking of DNA for Secret Storage*

ST. PAUL, Minn.—Three important court cases involving Baby DNA are in progress in Michigan, and while one has suffered a setback, litigators and parents are pressing forward to ensure that their children's genetic blueprint, and the genetic code of other newborn babies, is protected and kept private.

[Citizens' Council for Health Freedom \(CCHF\)](#), which first discovered state storage of newborn DNA in 2003, has been following the cases closely and was disappointed in the judge's recent ruling against Michigan parents in the federal case. These parents sued the State of Michigan for storing and using their child's DNA without their consent. The children's blood was taken at birth for the newborn genetic screening program and sent to the Michigan Neonatal Biobank, which holds the DNA of almost every child born in Michigan since 1987—more than 5 million children, many of them now adults.

The District Court judge in [Adam Kanuszewski, et. al. v. Michigan Department of Health and Human Services, et. al.](#) ruled that taking the DNA, without parental consent, did not amount to "harm" and therefore ruled in favor of the defense's motion to dismiss the case. But **CCHF** vehemently disagrees with the judge's reasoning.

"The government would like to say that taking the blood and DNA into government storage is not 'harm,'" said Twila Brase, president and co-founder of CCHF. "But this action, done without consent, is the harm."

"In the Michigan case, the judge's decision to limit the consideration of 'harm' to actions taken with the children's newborn blood samples after they are stored without their parent's consent is shortsighted," Brase added. "The retention is the first harm."

Brase pointed to additional "harms" that result from government storage of newborn DNA:

- The government essentially owns the DNA of every newborn through the newborn screening program. With this court case, the government has now claimed ownership and the judge has agreed.
- Legislators can come up with new things to do with Baby DNA, such as genetic sequencing and law enforcement.
- Not only has privacy been dismissed, but the ability to tell the government it cannot take DNA, blood or genetic property has also been dismissed.

- Patients don't realize the harm if they are unaware DNA has been stored and could be used against them or for activities to which they are opposed.
- Through DNA storage and research, another party can gain knowledge of the elements and biomarkers in the child's DNA and, therefore, have information on the subject, which the subject does not know.
- Once the storage is discovered, parents may experience fear of what the government and researchers have already done, and what they might do in the future. This too is harm.

In many states, newborn blood spots are stored without the parents' knowledge. Parents often see hospital staff take the blood, but they do not realize the hospital does not do the test. The hospital sends the blood spot card to the state government for testing—and, too often, storage.

“Proving the judge’s argument of harm, especially when everything is happening under the cover of darkness, can be difficult,” Brase said, “which is handy for those who want to take away the parent’s rights and the rights of the newborn citizen, who will be an adult in just 18 years. Michigan keeps the child’s DNA in a government warehouse in perpetuity—for 100 years or forever.”

Brase also noted that in Michigan prior to 2010, researchers were permitted to use newborn blood spots without parent consent or the consent of the individual who is now an adult.

Since 2010, newborn blood spots cannot be used for research without parent consent, but may be destroyed upon request, using an opt-out process that began May 1, 2010. Even though parents refuse consent for research, the blood spot can be used for newborn screening processes that could include test development, which, Brase says, is actually research. Read more [here](#) and see the parent opt-out form in Michigan [here](#). Read more about the Michigan BioTrust's information about newborn blood spots [here](#).

Attorney Philip L. Ellison has appealed the federal case on behalf of the Michigan parents at the U.S. Appellate Court. Ellison posts updates on the cases, as well as background, at www.StolenBlood.com.

Brase is the author of the new book, *“Big Brother in the Exam Room,”* published last month by Beaver's Pond Press. Besides a section on Baby DNA, the book exposes how and why Congress forced doctors and hospitals to install a data-collecting, command-and-control surveillance system in the exam room. The extensively researched work also includes the negative impact of EHRs on privacy, personalized care, costs, patient safety and more, according to doctors and data from more than 125 studies. *“Big Brother in the Exam Room”* is available at Amazon.com and www.BigBrotherInTheExamRoom.com.

For more information about *CCHF*, visit www.cchffreedom.org, its [Facebook](#) page or its Twitter feed @CCHFFreedom. Read more about *“Big Brother in the Exam Room”* [here](#), and view the [media page for CCHF](#) [here](#). For more about *CCHF*'s free-market, cash-based care 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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To interview Twila Brase of *Citizens' Council for Health Freedom* or for a review copy of *“Big Brother in the Exam Room,”* contact Deborah Hamilton, Media@HamiltonStrategies.com or 610.584.1096, ext. 102, or Patrick Benner, ext. 104.