

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

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NATIONAL DNA DAY | APRIL 25

Parents, Did You Know?

Citizens' Council for Health Freedom Alert—

Many States Store, Use and Share Newborn DNA for Research Without Consent; Most Parents Have No Idea

ST. PAUL, Minn.—In a world dominated by technology, surveillance and privacy concerns, there is very little that still truly belongs to human beings.

Their DNA should be one of these closely guarded possessions.

But from their very first day on Earth, the country's tiniest citizens are losing their rights to and privacy of their genetic blueprint because many states store, use and share newborn DNA for research—without parental consent, says [*Citizens' Council for Health Freedom \(CCHF\)*](#).

CCHF is bringing to light its important work for the protection and privacy of Baby DNA as National DNA Day approaches on April 25.

According to the National Human Genome Research Institute, found at genome.gov, “National DNA Day commemorates the successful completion of the Human Genome Project in 2003 and the discovery of DNA’s double helix in 1953. ... The goal of National DNA Day is to offer students, teachers and the public an opportunity to learn about and celebrate the latest advances in genomic research and explore how those advances might impact their lives.”

But to **CCHF**, National DNA Day should be about protecting the privacy of humans’ most private medical information—our DNA.

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 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.

Twila Brase, president and co-founder of **CCHF**, 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, several parent lawsuits have been filed, and judges have required millions of newborn DNA blood spot cards stored by state government to be incinerated. 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 all or most of the 35 genetic conditions [recommended](#) by a national panel. 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 access several state storage opt-out forms and learn more at its special “Baby DNA” web page: www.ItsMyDNA.org.

For more information about ***CCHF***, visit www.cchffreedom.org, its [Facebook](#) page or its Twitter feed @CCHFFreedom. Also view the [media page for CCHF here](#). 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.