

*****STATEMENT*****

For Immediate Release
June 11, 2019

Citizens' Council for Health Freedom Applauds Yesterday's Federal Appeals Court Ruling on Retention and Use of Newborn DNA in Michigan

Parents Rights Upheld to Protect their Children's DNA from State Retention, Transfer and Storage

ST. PAUL, Minn.— *Citizens' Council for Health Freedom (CCHF, www.cchfreedom.org)*, the organization that discovered state storage of newborn DNA in Minnesota in 2003, called on Minnesota's governor to destroy stored newborn DNA in [July 2007](#) and pulled Minnesota parents together in March, 2009 for the first lawsuit filed in the nation, applauds yesterday's [federal appeals court ruling](#) on retention and use of newborn DNA in Michigan.

CCHF also secured a parent consent amendment to the Newborn Screening Saves Lives Reauthorization Act of 2014 (required parent consent for use of newborn dried blood spots (Baby DNA) for federally-funded research). In addition, *CCHF* created a web page specific to the issue (itsmydna.org).

CCHF president and co-founder Twila Brase released the following statement in response to yesterday's newborn DNA announcement in Michigan:

“We applaud yesterday’s federal appeals court ruling on retention and use of newborn DNA. The Sixth Circuit Court of Appeals recognized the fundamental and Fourth Amendment rights of parents to protect their children’s DNA from state retention, transfer to a biobank, and long-term storage and remanded it back to the federal district court ‘for further proceedings consistent with this opinion.’

“The court is rightly concerned about the state of Michigan storing, using and sharing newborn DNA for purposes beyond the initial detection and treatment of newborn conditions that are life-threatening. And the parent-plaintiffs are rightly concerned about a state-funded biobank that holds newborn DNA in perpetuity for the purpose of conducting genetic research using newborn DNA without consent or with consent under duress. As a [2013 study](#) found,

'Formally marketing double de-identified newborn screening dried blood spots (DBS) for health research, Michigan is home to one of the largest biobanks in the United States. Run by the Michigan Department of Community Health, the BioTrust offers a collection of biospecimens whose size, unbiased sampling and linkability to public health data make it a ‘goldmine’ [2] for public health assessment and a potential key to important health questions.'

“We’re also pleased that the court recognized that newborn genetic testing may present a risk of future harm. The court essentially invites pregnant women to bring such a lawsuit for their consideration ‘which would require us to address the merits of’ the issue of harm due to the screening without parent consent.

“As this case proceeds in the federal court system, Citizens’ Council for Health Freedom looks forward to the possibility of securing parent consent requirements nationwide prior to the storage and use of newborn DNA. We would also like the courts to recognize that requests for parent consent that happen when parents are vulnerable, in the fatigue and fog of the post-delivery period, are not true consent. Too often parents have no idea what they are signing and do not recall doing so. They think it’s just another hospital form.

“As studies and news reports prove, parents are deeply concerned about protecting their child’s genetic privacy. This case should not only set a standard for parent consent requirements for state bio-banking and use of newborn DNA, it should also set a standard for true consent, a process that forbids the state from exploiting the vulnerability of parents post-delivery when parents can least protect their newborn children’s genetic privacy rights.”

Brase writes extensively about protecting Baby DNA, as well as socialized medicine, patient privacy, electronic health records, health freedom and how the Affordable Care Act has harmed patients and doctors since 2010 in the new book ***“Big Brother in the Exam Room: The Dangerous Truth About Electronic Health Records.”*** For more information, visit BigBrotherintheExamRoom.com.

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