As of August 1, It’s Been 5 Years Since Minnesota Resumed Storing and Using Baby DNA After a Parent Lawsuit Forced Them to Stop

Citizens’ Council for Health Freedom: Parents in Every State Need to Know If Their Newborn’s Genetic Blueprint Is Being Stored and Used

ST. PAUL, Minn.—More than 15 years ago, Citizens’ Council for Health Freedom (CCHF, www.cchfreedom.org) discovered that the Minnesota Department of Health was storing and using Baby DNA—the genetic blueprints of its youngest citizens obtained through newborn screenings—without parental consent.

That 2003 discovery led to many years of advocating on behalf of parents across the state. By July 2007, CCHF had called on Minnesota’s governor to destroy stored newborn DNA. Two years later, in March 2009, CCHF organized a group of Minnesota parents to file the first lawsuit in the nation aimed at protecting Baby DNA. After the Minnesota Supreme Court ruled that the storage and use was in violation of the state genetic privacy law, the state was required to destroy all baby DNA specimens, which had been kept without parental consent since July 1, 1997.

“Unfortunately, said Brase, the Minnesota legislature changed the law, pulling the newborn screening program out of the protective genetic privacy law, and storage began again without parental consent on Aug. 1, 2014. So, for the past five years, newborn DNA has been stored and used by the state health department in Minnesota without parent consent.”

While CCHF works at a federal level to require parent consent for use of newborn DNA for federally-funded research, the organization encourages parents to act to protect their children.

“Parents can take legal action,” Brase said. “A group of parents in Michigan recently experienced a legal victory when 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 the case back to the federal district court.”

In some states, parents may also opt out of having their child’s DNA stored or used by completing a form, such as in Minnesota. The CCHF website, www.itsmydna.org provides a 50-state retention schedule for parents to check how long the state where their child was born keeps newborn DNA after newborn genetic screening.
“We encourage parents to be informed about state policies regarding Baby DNA,” said Brase. “Some store DNA for a short time, while others store and use it indefinitely, often without parental consent.”

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.

Learn more about CCHF at www.cchfreedom.org, its Facebook page or its Twitter feed @CCHFreedom. 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.

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