***NEWS RELEASE***

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CONTACT:
John Sonnen, Communications Manager, media@cchfreedom.org, 651-382-6158

ST. PAUL, Minn. — Reacting to today’s CBS new story on the privacy of newborn dried blood spots stored after newborn genetic screening, Citizens’ Council for Health Freedom releases the following statement from Twila Brase, CCHF’s president and co-founder:

“Newborn blood spots, the DNA of America’s children, have been called a “national treasure,” but this treasure should never become the property of the state as it is in many states today. Attorney Philip Ellison’s work to restore newborn genetic rights and parental consent rights over newborn DNA is critical to restoring these fundamental rights nationwide.

“Parents often have no idea that the long arm of state government has reached into the hospital and taken their newborn’s DNA for storage and research. Many parents in the fog of labor and delivery leave the hospital filled with the joy of having a new baby. They have no idea that state government officials have analyzed their child’s blood for newborn genetic screening, put the results in a government database, stored their child’s DNA in a state repository, used it for state research and test development, given it away to medical and genetic researchers, and shared it with others, such as law enforcement or the U.S. government.

“It is illegal for states to take the DNA of adults without their consent, but in what is considered the largest population-wide genetic testing program in the country, states are taking and many are retaining the DNA of newborn citizens without the knowledge or consent of the parents, and without the later consent of the minors who have become adults. In 2014, Indiana had 666 banker boxes filled with 23 years of newborn DNA. This ongoing violation of genetic privacy rights and the right of parents to protect their child from genetic exploitation and involuntary participation in research must end.”

For information on state retention rates of newborn DNA, click here.

Citizens’ Council for Health Freedom first discovered state government storage of newborn DNA in 2003 in the state of Minnesota. In 2009, the organization’s efforts included the orchestration of the first parent lawsuit filed in the nation against state government storage, use, and dissemination of newborn DNA without parental consent. In 2014, CCHF secured a temporary federal law requiring parental consent for use of newborn DNA for federally funded
research. CCHF continues to work at the federal and state level to secure parental consent requirements for analysis, storage, use and dissemination of newborn DNA.

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Citizens’ Council for Health Freedom exists to protect patient and doctor freedom. As a national health freedom policy organization, CCHF maintains a patient-centered, privacy-focused, free-market perspective. For more information visit: www.cchfreedom.org.

Twila Brase, President and Co-founder of CCHF, has been interviewed extensively by Science and Nature on the subject of Baby DNA storage and use. She is the author of the eight-time, award-winning book, Big Brother in the Exam Room: The Dangerous Truth about Electronic Health Records (2018), which includes a section on newborn DNA, and which was just re-released in its third printing, this time with the often-requested index. http://www.bigbrotherintheexamroom.org/

To request an interview with Twila Brase, call 651-382-6158 or email John Sonnen at john@cchfreedom.org.