

\*\*\*NEWS RELEASE\*\*\*

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## **Settlement Reached in Minnesota Case of Baby DNA Stored Without Consent**

### *CCHF Calls for Immediate Destruction of More Than 1 Million Blood Samples That Were Secretly Stored for Research*

**ST. PAUL, Minn.**—The start of 2014 marks a victory for the protection of private genetic data with the settlement of a lawsuit between 21 Minnesota families and the Minnesota Department of Health. The multi-year case argued the illegal and improper storage and use of newborn blood samples and genetic test results obtained under the Newborn Screening Program by the state health department. The ruling is in favor of the 21 plaintiffs, and now the blood samples and test results obtained without consent must be destroyed.

The Minnesota Department of Health had secretly established a database of genetic test results and a DNA bio-bank of blood samples from blood left over after newborn screenings. More than 50,000 blood samples and test results were also given by the State to drug companies and equipment manufacturers for genetic and other research—without parental knowledge or consent.

The Minnesota Supreme Court ruled in November 2011 that written, informed consent is required for storage, use and dissemination of any remaining blood samples and test results after completion of newborn screening, and then remanded the case for trial to determine remedies. As part of the settlement, the department has agreed to comply with newborn screening and genetic privacy laws which were changed in 2006 to require written informed consent from parents prior to storage or use of the child's DNA or genetic test results.

**Twila Brase**, patient advocate and co-founder of *Citizens' Council for Health Freedom*, has followed the case closely and said she is pleased that the health department has been found at fault but disappointed that all the children and families whose privacy rights have been violated were not allowed to participate in the case.

***“We are disappointed that the court refused to accept the class action lawsuit. The Minnesota Department of Health has been storing and using private genetic information taken from all newborns without consent and without any legal authority since July 1, 1986,” Brase said. “This unlawful seizure of private genetic information began with a secret executive decision. It continued***

*despite the enactment of the 2006 state genetic privacy law, even after an administrative law judge ruled the department in violation of the genetic privacy law. The department's willful action has cost taxpayers significant dollars in litigation and provides the public with one more reason not to trust public health officials or the integrity of the government's Newborn Screening Program."*

**Brase** added that she and concerned members of the public want assurance that the DNA blood samples and genetic test results will actually be destroyed.

*"The state represented to the court and to the 2013 legislature that they will destroy the newborn DNA bloodspot cards and the genetic tests that have been and are today still warehoused without consent. The Minnesota Department of Health must now formally confirm to the public and to the state legislature the date, time and process used for the destruction of these blood samples and test results stored without parental consent. That which was done in secret must now be destroyed with transparency," she said.*

For further information or legal details on the case and the settlement, visit [www.itsmydna.org](http://www.itsmydna.org) and [www.farrishlaw.com](http://www.farrishlaw.com).

**Twila Brase** shares health care-related news with the public in her daily, 60-second radio feature, **Health Freedom Minute**, which airs on more than 150 stations nationwide on the American Family Radio Network and 80-plus stations on the Bott Radio Network. During the daily features, listeners can learn more about the agenda behind proposed health care initiatives and policies and what they can do to protect their health care choices, rights and privacy.

**Brase**, a public health nurse and health care freedom advocate, informs listeners of crucial health issues, such as the intrusive wellness and prevention initiatives in Obamacare, patient privacy and the need for informed consent requirements, the dangers of "evidence-based medicine" and the implications of state and federal health care reform.

***Twila Brase**, has been called one of the "100 Most Powerful People in Health Care" and one of "Minnesota's 100 Most Influential Health Care Leaders." She has been interviewed by CNN, Fox News, Minnesota Public Radio, NBC Nightly News, NBC's Today Show, NPR, New York Public Radio, the Associated Press, Modern Healthcare, TIME, The Wall Street Journal, The Washington Post and The Washington Times, among others. **Brase** shares health care-related news and commentary with the public in her daily, 60-second radio feature, **Health Freedom Minute**, which airs on nearly 350 stations daily, including the 150-station American Family Radio Network and the 80-station Bott Radio Network. **Health Freedom Minute** is sponsored by the **Citizens' Council for Health Freedom**, a patient-centered national health freedom organization based in St. Paul, Minn. **CCHF** supports patient and doctor freedom, medical innovation and the right of citizens to a confidential patient-doctor relationship.*

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For more information or to interview **Twila Brase**, president and co-founder of **Citizens' Council for Health Freedom**, contact Deborah Hamilton, Hamilton Strategies, 215.815.7716, 610.584.1096, [DHamilton@HamiltonStrategies.com](mailto:DHamilton@HamiltonStrategies.com).