



NEWS RELEASE

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Twila Brase of *Citizens' Council for Health Freedom* to Testify at Baby DNA Meeting

*After State Health Department Ordered to Destroy Test Results,
New Bill to Eliminate Parent Consent Introduced*

ST. PAUL, Minn.—Twila Brase, patient advocate and co-founder of *Citizens' Council for Health Freedom*, a Minnesota-based national organization with a goal to preserve patient-centered health care and protect patients' rights, will testify before the Minnesota State House of Representatives Health and Human Services Committee tomorrow regarding parental consent and the storage and use of baby DNA.

The meeting is set for 2:15 p.m. Wednesday, March 5 in Room 200 in the State Office Building.

Brase sent an alert to *CCHF* supporters and friends yesterday after five hospital executives wrote an opinion article in Friday's Star Tribune newspaper, stating why a new Minnesota bill should be passed—one that would repeal parental consent requirements regarding the long-term storage and use of baby DNA and newborn screening test results in a government warehouse and database.

“This practice that has long intruded on the privacy of Minnesota families and our state’s youngest residents was decided in the Minnesota Supreme Court,” Brase said. “And now hospital executives want to change that decision so they can keep collecting and using baby DNA and other data for genetic research without parental consent. It is as though they believe a person’s genetic code is state government property.”

The Minnesota Chapter of the American Academy of Pediatrics and other organizations are urging legislators to pass this newborn-screening bill which would eliminate hard-won parent consent requirements.

In January, *CCHF* and residents of Minnesota scored a victory for patient freedom and the protection of private medical data with the settlement of a Minnesota Supreme Court case that pitted 21 Minnesota families against the Minnesota Department of Health. The multi-year case argued against the illegal and improper storage and use of blood samples obtained under the Newborn Screening

Program by the state health department. The ruling was in favor of the plaintiffs, and the settlement directed those samples and test results obtained without consent be destroyed.

Starting in 1986, the Minnesota Department of Health secretly established a database of newborn genetic test results and in 1997 a bio-bank of blood samples left over after newborn screenings. They had no legislative authority. More than 50,000 blood samples and test results were used for research for drug companies and equipment manufacturers—without parental knowledge or consent.

The Minnesota Supreme Court ruled in November 2011 that written, informed consent is required for storage, use or dissemination of any remaining blood samples or test results after completion of newborn screening, then remanded the case for determination of remedies. The decision last month called for the health department to destroy more than a million blood samples and 900,000 test results. As part of the settlement, the department agreed to comply with newborn screening and genetic privacy laws.

The lawsuit settlement also resulted in a change in the law. The legislature specifically mandated written, informed consent before blood samples left over after testing under the newborn screening program can be used for any research, public health study or the development of new screening tests—a significant protection for newborn children and their families now. But this legislation would eliminate written informed consent requirements, virtually eliminating genetic privacy going into the future.

CCHF's efforts have led to lawsuits in Texas, as well as changes in law and regulations in various other states, such as Oklahoma, California and New York.

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 90-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.

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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.