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Patient Freedom Advocate Says Minnesota on Precipice of Repealing Genetic Privacy

*Citizens’ Council for Health Freedom’s* Twila Brase Says House and Senate Committees Have Stripped Parents of Consent

ST. PAUL, Minn.—Minnesota State House and Senate committees have passed a controversial bill on genetic privacy that would strip parents of initial right of consent in having their baby’s DNA researched and stored indefinitely.

The House Civil Law Committee recently passed the bill by a vote of 9-8, and the proposed law will now go to the House floor for a full House vote. Last week, the Senate Judiciary Committee also passed a companion bill, and soon all state Senators will vote on the law.

*Citizens’ Council for Health Freedom* (CCHF, [www.cchfreedom.org](http://www.cchfreedom.org)), a Minnesota-based national organization with a goal to preserve patient-centered health care and protect patient and privacy rights, has been working for 11 years to protect baby DNA. Twila Brase, patient advocate and co-founder of CCHF, which is marking its 20th anniversary this year, testified extensively on the matter and says now is the time for the public to become involved and speak up.

“Minnesota is on the precipice of repealing genetic privacy,” Brase said. “This controversial bill unravels a 2011 Supreme Court decision requiring parental consent before baby DNA is permanently filed with the government and allows the state to store and use baby DNA for research—indefinitely. If we step over this precipice, baby DNA will, by default, become the property of the state. Sure, parents can opt-out, but only if they know about the practice. At such a stressful time in parents’ lives, their privacy and that of their newborn baby should be protected, not stripped.

The proposed legislation would repeal parental consent requirements and make it legal for the state health department to store the test results and a newborn’s genetic information indefinitely for genetic research. Parents can opt out but only if they know about the practice.

Brase says there are several ways the public can let lawmakers know that they are against passage of the bill that will compromise their children’s genetic privacy:

* CCHF  161 St. Anthony Ave, Ste 923  St. Paul, MN 55103  651-646-8935  [www.cchfreedom.org](http://www.cchfreedom.org)
• Contact their state Senators and local Representatives to express opposition to the bill. State lawmakers and their contact information may be found at the following links:

  **SENATORS:** [http://www.senate.leg.state.mn.us/members](http://www.senate.leg.state.mn.us/members)

  **REPRESENTATIVES:** [http://www.house.leg.state.mn.us/members/hmem.asp](http://www.house.leg.state.mn.us/members/hmem.asp)

• Write letters to the editor of local newspapers opposing the bill.

• Contact **CCHF** by emailing [info@cchfreedom.org](mailto:info@cchfreedom.org) to learn how to become involved in initiatives to stop the passage of the bill.

**CCHF** was instrumental in a victory for patient freedom and the protection of private genetic data with the settlement of a Minnesota Supreme Court case in November 2011. The multi-year case pitted 21 Minnesota families against the Minnesota Department of Health, with parents charging the department with illegal and improper use of blood samples obtained under the Newborn Screening Program. The ruling was in favor of the plaintiffs, and now those samples and test results obtained without consent must be destroyed. The new bill would nullify the privacy protections gained by the ruling.

According to a special section of **CCHF**’s web site called [ItsMyDNA.org](http://ItsMyDNA.org), every state has a mandatory newborn screening program to test for serious genetic disorders and genetic traits in newborns. Within 48 hours after the birth of a baby, the heel is pricked, newborn blood is squeezed onto a card with special filter paper, and the card is sent for analysis to the state government laboratory or the laboratory under contract with the state department of health. At least 4 million newborn babies are tested every year in the United States.

The ACLU of Minnesota also testified against the passage of the bill, stating that the bill is a “dangerous effort to enable unlimited retention and minimize parental consent, allowing newborn blood samples to be used at the whim of the government and researchers, rather than through the consent of the newborn and their family.” The ACLU also added that the bill is “problematic for numerous reasons. It represents a radical departure from traditional practice. It implicates important privacy and self-determination interests. The information is not anonymous. Finally, obtaining informed consent for the retention and later use after newborn screening for all purposes is not only possible but practical.”

**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