



MEDIA RELEASE

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It's the Law

When will Governor Pawlenty protect the genetic privacy and DNA property rights of Minnesota's youngest citizens?

August 1, 2009 marks the start of the 4th year state government health officials have intentionally violated the MN genetic privacy law

(St. Paul/Minneapolis) – Marking the third anniversary of the 2006 Minnesota genetic privacy law (M.S. 13.386), the Citizens' Council of Health Care (CCHC) held a press conference to call on Governor Tim Pawlenty to require the Minnesota Department of Health to comply with the law's informed written consent requirements regarding the collection, storage, use, and dissemination of baby DNA and newborn genetic test results.

The press conference brought together concerned citizen groups and highlighted a new study published in *Public Health Genomics*: "Not without my Permission: Parents' Willingness to Permit Use of Newborn Screening Samples for Research."

Speaking at the press conference were a mother of two children and executives of the Human Life Alliance, MN Campaign for Liberty, and the Minnesota Family Council.

Twila Brase, CCHC president, said, "The 2006 Minnesota genetic privacy law requires informed written consent for the collection, storage, use and dissemination of genetic information. It's the law. Yet every day—despite a 2007 judge's ruling that found the Minnesota Department of Health in violation of the law—state health officials continue to store newborn blood in a government Baby DNA repository, retain newborn genetic test results in a State genetic registry, and use and share private genetic information for genetic research. This is all being done without parent consent and in violation of the state genetic privacy law."

Mrs. Diana Waletzko, a mother from Woodbury, Minnesota, said, "Even if no one within the government has a malicious intent, I do not trust the government to keep my

children's DNA and genetic test results secure. I don't even want to think about what kind of discrimination could happen with every baby's DNA on file at the government."

Pointing to the recent study on parent attitudes regarding storage and use of newborn DNA, CCHC president **Twila Brase** said, "While the study shows that many parents may be willing to permit storage and participate in genetic research, it's very clear that most parents are not willing unless they have first been asked for permission."

Jo Tolck, executive director of Human Life Alliance, discussed concerns regarding use of the stored genetic test results, saying, "We are concerned that DNA test results obtained from blood samples taken from newborns will be used against the child, future children and the parents. We are also concerned that these DNA test results could be used to pressure parents not to have subsequent children and to possibly deny health insurance for the child tested as well as future children."

Marianne Stebbins, president of MN Campaign for Liberty urged the preservation of liberty through the protection of personal privacy, saying, "The most elemental makeup of a person is one's DNA. In Minnesota, privacy rights related to DNA are being violated at birth. Preserving individual liberty requires maintaining both the rule of law and privacy of person."

Tom Prichard, executive director of the Minnesota Family Council added, "Parents, children and families have legitimate medical, privacy interests that need to be protected. It is the responsibility of state government to facilitate and not hamper these legitimate privacy interests. Health department compliance with the Minnesota genetic privacy law is essential for the protection of individual and family privacy now and in the future."

Ms. Brase issued a call to the Governor, saying, "We call on Governor Pawlenty to protect the genetic privacy and DNA property rights of all citizens. On behalf of concerned Minnesota parents and families, we call on the Governor to take immediate steps to require the Minnesota Department of Health to comply with the informed written consent requirements of the 2006 Minnesota genetic privacy law."

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Citizens' Council on Health Care supports freedom for patients and doctors, medical innovation, and the right to a confidential patient-doctor relationship.

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