

MEDIA RELEASE

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For Immediate Release

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Governor Pawlenty's Letter Reveals Plan to Eliminate Current Genetic Privacy Protections from Baby DNA

Letter to CCHC is deceptive dodge of judge's ruling

Minneapolis/Saint Paul – Today, Citizens' Council on Health Care (CCHC) released a letter sent to CCHC and signed by Minnesota Governor Tim Pawlenty. The Governor was responding to a letter faxed to him by CCHC on July 24, 2007.

“The Governor’s letter was not the response we hoped for. Governor Pawlenty ignores 10 years of illegal government possession of the DNA of babies, reveals a plan to eliminate current genetic privacy law protections for baby DNA, and is dismissive of the decisions of two judges, says Twila Brase, CCHC’s president.

“The present intrusive activities based on the alleged authority of a law that does not exist, and the Governor’s plan to eliminate the privacy protections of a law that *does* exist is an outrage against the citizens of Minnesota,” she says.

Governor Pawlenty’s letter is available online at <http://www.cchconline.org>.

Brase says Governor Pawlenty’s response does not address the public’s concerns:

- **Refers to a Non-Existent “Law”** – Governor Pawlenty states in the letter, “I believe the legislative intent is unclear concerning the destruction of bloodspots.” The Governor’s statement ignores the facts as noted by Administrative Law Judge Barbara Neilsen in her March 23, 2007 ruling: Minnesota law does not provide the Department with any statutory authority to retain, store or disseminate newborn blood and DNA. *There is no “legislative intent” because there is no law and never has been a law allowing the storage and secondary use of newborn blood and baby DNA.*

- **Elimination of Current Genetic Privacy Rights** – Governor Pawlenty will require his staff to write legislation clarifying the “parent’s right to decline” use of their baby’s blood for research studies. Notably, he will not require legislation to clarify explicit parent consent rights currently required by the 2006 Genetic Privacy Law. Thus, as was attempted during the final days of last session—after the judge’s ruling—the Governor’s staff will again try to exempt the newborn genetic testing program from the parent consent requirements of the 2006 law. *Only the right of consent empowers the people. The right to decline always empowers the government.*
- **No Acknowledgement of Unlawful Behavior by State Health Officials** – Governor Pawlenty’s letter ignores the fact that the Minnesota Department of Health has been working outside the law, storing the blood and DNA of babies and giving it to genetic researchers. In his letter, the Governor hides behind the Chief ALJ Raymond Krause “clarification” letter that was requested by Health Commissioner Dianne Mandernach after Judge Krause denied her appeal—and after she withdrew the newborn screening rule to avoid his decision. *Already, this “clarification” letter is being used by the Department and the Governor to build a case for continued government possession of illegally retained and improperly used baby DNA.*
- **Avoids Public Process and Public Accountability** – Governor Pawlenty does not require the Minnesota Department of Health (MDH) to revise the current newborn screening rule to include Judge Neilsen’s and Chief ALJ Raymond Krause’s requirements. The Governor only asks health officials to revise their written materials in-house and at their own discretion. *This behind-closed-doors operation by health officials, who have fought and disregarded all attempts to require full disclosure to parents about newborn (genetic) screening, will not enable public accountability within the required open and public process of rulemaking—and whatever revisions are made can be changed without public notice at any time.*

Three Questions

“The public should be asking three questions: Why does Governor Pawlenty support the elimination of current parent consent rights? Why does the Governor refuse to require his staff to follow state law? And why does Governor Pawlenty want a required public process to stay behind closed doors?” says Brase.

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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.