



Citizens' Council on Health Care

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DUPLICATE

July 24, 2007

Governor Tim Pawlenty
Office of the Governor
130 State Capitol
Saint Paul, MN 55155

Dear Governor Pawlenty,

We are asking for your immediate attention to an issue of vital interest to the public, and the rights of all citizens.

On March 27, 2007, Judge Barbara Neilsen stated the following in her newborn screening ruling:

“There is no express authorization in the newborn screening statute for the Department’s current practice of retaining the information indefinitely without consent and permitting the information to be used without consent for purposes other than the detection, treatment, and follow-up of heritable and congenital disorders as contemplated by the newborn screening statute.”

Judge Neilsen then ruled that informed consent was required for such storage and use by researchers.

During the 2007 session, MDH tried to exempt the newborn screening program from the state genetic privacy law, saying the Department would be required to destroy the newborn blood specimens if they did not receive an exemption. The legislature did not provide that exemption.

The health department then appealed the judge’s decision on June 26, 2007, and the appeal was also denied, this time by Chief Administrative Law Judge Raymond R. Krause on July 3, 2007.

Ten years ago, the Department made an executive decision that was outside the laws of the State of Minnesota. As Judge Neilsen stated, without any legal standing, they began to collect and store newborn blood indefinitely. They also began providing it to medical researchers without legal standing, parent knowledge or consent.

On July 12, 2007, we sent a letter to Commissioner Dianne Mandernach requesting that all stored newborn blood specimens be destroyed by August 9, 2007, including those that have been provided to medical researchers (*letter enclosed*). We asked for her to provide us with a response within a week confirming her intent to destroy the blood specimens along with a schedule for that destruction, yet Commissioner Mandernach has chosen not to respond.

Therefore, Commissioner Mandernach and the state health department do not seem any more inclined to follow state law now than in 1997 when the Department began storing newborn blood without legal authority or parent consent.

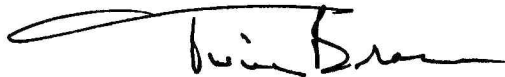
No state agency is outside the law, including the Minnesota Department of Health.

Your administration should set an example by immediately moving to obey state law.

We are requesting that you, as Governor and head of your administration, take action immediately to require Commissioner Mandernach and the Minnesota Department of Health to destroy all the newborn blood specimens.

It is reasonable to request that you to move on this by Tuesday, August 14, 2007. Please advise me of your intentions by Tuesday, July 31, 2007.

Sincerely,

A handwritten signature in black ink, appearing to read "Twila Brase". The signature is fluid and cursive, with a long horizontal flourish at the beginning.

Twila Brase
President

Enclosure