MN Supreme Court Says State of Minnesota in Violation of MN Genetic Privacy Law

The Minnesota Supreme Court has ruled that the Minnesota Department of Health is violating the Minnesota Genetic Privacy Law with its storage, use and dissemination of newborn screening test results and newborn DNA.

"We are cheered by this good news, says Twila Brase, president of CCHF. "When our organization discovered the state health department's Baby DNA warehouse in 2003 and the use of newborn DNA for genetic research without parent consent, we determined to do all that we could to stop this practice. No state law expressly permits these activities."

"We are pleased that these nine families were willing to sue the State of Minnesota," adds Brase. "Their action and this decision now secures the genetic privacy rights and informed written consent rights of all Minnesota parents and newborn citizens."

Justice Helen M. Meyer, voicing the majority opinion in the ruling, writes:

"The Genetic Privacy Act ... restricts the collection, use, storage, and dissemination of blood samples collected pursuant to the newborn screening statutes...

"The newborn screening statutes provide an express exception to the Genetic Privacy Act only to the extent that the Department is authorized to administer newborn screening by testing the samples for heritable and congenital disorders, recording and reporting those test results, maintaining a registry of positive cases for the purpose of follow-up services, and storing those test results as required by federal law."

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