MINNESOTA HIGH COURT AFFIRMS GENETIC LAW'S PRIVACY SAFEGUARDS

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The Minnesota Supreme Court has ruled that the state's Health Dept. has been violating the Minnesota Genetic Privacy Law with its storage, use and dissemination of newborn screening test results and newborn DNA.

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Under the Minnesota program, if a portion of the blood sample remains after the screening tests are completed, the sample is retained indefinitely unless there is a specific request to have it destroyed. As of January 2009, there were more than 800,000 newborn screening samples in storage, dating back to samples taken as early as 1997. More than 50,000 blood samples have been used in studies for purposes beyond the initial screening of the newborn children. These studies have included developing new tests and assuring the quality of existing tests. Blood samples have also been used for studies unrelated to the newborn screening program. A blood sample is capable of being used for research for up to 20 years.

The State asserted that a federal law requires it to retain newborn screening test results for two years.

While the Genetic Privacy Act's places some restriction on collection and use of genetic data, which includes the children's blood samples, the court said the State Health Dept.'s newborn screening programs did not violate these restrictions.

However, the court found the department ran afoul of the storage restrictions, despite an exception allowing for a 45-day window. "But even if this provision authorizes the

Commissioner to retain genetic information for 45 days before complying with a destruction request, it does not expressly provide for indefinite storage when no destruction request is received. Section 144.128 is silent on the question of how long genetic information may be retained, and therefore the statute cannot be an â€—express' exception to the Genetic Privacy Act's opt-in framework," wrote Justice Helen M. Meyer.

The court also said the department's uses and disseminations went beyond the Act's specific exceptions.

"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," she wrote. "The newborn screening statutes do not expressly authorize the Department to conduct any other use, storage, or dissemination of the blood samples." (Alan & Keri Bearder, et al.: Minn. Supreme Ct. â€“ No. A10-0101; Nov. 16.)

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