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The state's screening program requires newborns to be screened for disorders before leaving the hospital. In 2002, the state began to store the samples indefinitely.

State seeks way to allow destruction of some blood samples

Some parents upset that newborn screening is done without their consent.

By **Mary Ann Roser**

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The state health department said Thursday that it is trying to figure out a way to legally destroy newborn blood samples that parents don't want stored indefinitely and possibly used for research.

"We will try to honor these requests if we legally can, but we have to work out a process for legally doing that," said Doug McBride, spokesman for the Department of State Health Services.

Although no law requires the department to store the blood samples or use them for research, officials said they need to resolve issues such as verifying that the request is from the child's parent, McBride said. The department wants requests in writing.

Four parents have contacted the department asking that samples be returned or destroyed since an article about the practice first appeared in the Austin American-Statesman Feb. 22, McBride said. The article described a part of the state's 44-year-old mandated newborn screening program in which hospitals, birthing centers and midwives draw blood from a baby's heel — no parental consent is required — so the state can test for a variety of birth defects.

Under the health department's policy, the samples, which consist of five blood spots on a card, can be used by the medical community for things such as cancer research, birth defects studies and calibration of lab equipment. The law doesn't require that parents be told how the blood might be used, but Texas allows parents to opt out of the screening only for religious reasons.

Starting in 2002, the health department began storing the blood spots indefinitely. A similar provision allowing indefinite storage of newborn blood spots in Minnesota resulted in a legal

challenge by a consumer group concerned about lack of consent, the potential for patient privacy violations and concerns about future discrimination.

Researchers say the blood samples are an important tool for their research. Jacqueline Hecht, vice chairwoman for research at the University of Texas Medical School at Houston, said without access to the blood samples, "we might miss the opportunity to make huge breakthroughs to help humanity."

Some parents, however, said they were livid that their child's blood had become state property.

The state considers the stored samples to be "de-identified" because the samples are stored at Texas A&M University's School of Rural Public Health in Bryan without identifying information on the cards. Each card bears a code number instead of a name, McBride said. The names matching those codes are kept at the state health department in Austin and are not released to researchers without parental consent, he said.

Keith Taylor said that when his daughter was born at Clear Lake Regional Medical Center in Webster in January, he declined the newborn screening tests because of privacy concerns. He said he told the hospital he "wanted to keep control of her bodily fluids" but was informed by staff that the newborn would not be going home with him and his wife if they did not agree to the tests. Taylor said he "grudgingly allowed them" to do the testing but later contacted the state to get the sample back.

The hospital did not return a call Thursday seeking comment.

Another parent from Houston, Jeremy Poland, said he was so angry after reading a reprint of the Statesman article that when his son was born at St. Luke's The Woodlands Hospital on Feb. 26, he contacted the state health department asking that the blood be destroyed after screening. He succeeded in declining the test at the hospital for religious reasons and found a private lab at Baylor Hospital in Dallas to do the testing. Consequently the storage issue became moot, he said.

"One nurse said in 29 years, she hadn't seen anyone disengage from the state test," Poland said.

State health officials do not plan to return blood, seek consent or make it possible for new parents at the hospital to opt out of the indefinite storage part of the program, McBride said.

They're concerned that if the law is changed, children might not get screened for detectable disorders, especially ones that, if treated early, could prevent disabling disorders.

Parents who want to request that blood samples be destroyed should send letters to Newborn Screening Lab, Texas Department of State Health Services, P.O. Box 149347, Mail Code 1947, Austin, TX, 78714-9347. They will receive a response with information on the department's plans for dealing with such requests, McBride said.

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