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State agrees to destroy more than 5 million stored blood samples from newborns

Destruction of samples stored for possible medical research ends lawsuit against state.

To settle a lawsuit, the state has agreed to destroy more than 5 million blood samples from newborns that it had stored indefinitely for possible research without parents' consent, the two sides said Tuesday.

The Texas Civil Rights Project filed the lawsuit in U.S. District Court in San Antonio in March on behalf of four parents and a pregnant woman who dropped out later. It claimed that the state's collection and storage of the samples amounted to "an unlawful search and seizure" and violated the privacy rights of the parents and their children. Under the settlement, the state will destroy 5.3 million samples it has collected between 2002, when the Department of State Health Services began storing the blood, and May 27, when a new state law restricting the practice was signed.

Federal Judge Fred Biery approved the settlement agreement Dec. 14 and gave the state 120 days — until April 13 — to finish destroying the samples, which are stored at Texas A&M University's School of Rural Public Health.

This year, when stories in the American-Statesman brought the practice to light, the state health department and some medical researchers defended it, saying that collecting the blood spots on paper — done when newborns are screened for various health disorders — might one day provide valuable clues about childhood cancer and other diseases. They said that because the samples were coded and did not identify the babies by name, privacy rights were protected.

But the Texas Legislature approved a law in May requiring medical professionals to inform parents or guardians that the blood spots would be collected and stored indefinitely and could be used for research. Parents who objected could send a statement to the state health department, and their child's samples would have to be destroyed within 60 days. If the parents didn't do that, the child could upon reaching adulthood.

Between the time the law passed and Nov. 2, about 6,900 Texans have signed forms asking that the state destroy their child's samples, out of 240,000 children born in that period, department spokeswoman Allison Lowery said. The department is getting 500 to 600 requests a week to destroy samples, she said.

A statement from the state health department said it "believes settling this lawsuit is in the best interest of this program's core mission to screen all newborn babies in Texas for life-threatening

disorders. Newborn screening saves children's lives, and settling this lawsuit allows us to continue operating this critical program."

Jim Harrington, director of the nonprofit civil rights group in Austin, said his organization was "very pleased with the way it worked out."

Harrington said there were only two options to end the lawsuit: destroy the samples or try and go back to 2002 and get consent from all parents. About 400,000 babies a year are born in Texas.

Among the parents who sued was Austin lawyer Andrea Beleno, Harrington's daughter-in-law. Her son Joaquin Harrington was born in November 2008, and Beleno said she had no idea "in the haze after giving birth" that any blood had been drawn and stored.

"To me, this whole thing was about consent," she said. "If they had asked me ... I probably would have consented. The fact that it was a secret program really made me so suspicious of the true motives, there's no way I would consent now."

Harrington said he will work with a legislative committee before the next regular session in 2011 to refine the new law.

He wants the state to divulge what research it is using the samples for and whether anyone is making money from it. He also wants to see how well the "opt out" provision is working.

Many other states do what Texas had been doing, and a consumer group in Minnesota has been fighting the practice there for several years.

"The State of Texas has taken first steps to restoring the genetic privacy rights of Texas children. This is a wonderful Christmas present for Texas citizens," Twila Brase, president of the Citizens' Council on Health Care in St. Paul/Minneapolis, said in a statement.

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