



TEXAS CIVIL RIGHTS PROJECT
EQUALITY - JUSTICIA - DIVERSITY - COMUNIDAD

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TCRP LAWSUIT ON SECRETIVE COLLECTING AND STORING NEWBORN BLOOD SAMPLES BRINGS ABOUT PROTECTIVE LEGISLATION— HB 1672

The federal lawsuit filed in March by the Texas Civil Rights Project on behalf of five parents has resulted in new state legislation to protect the state's access to people's genetic information. The legislature sent the law to the governor today for signature.

The lawsuit sought to end the practice of the Texas Department of State Health Services from collecting and indefinitely storing blood samples from the blood screening done at childbirth without parental consent or disclosure to the parent – a secretive practice the health department has engaged in since 2002. Currently, about 4 million samples stored at Texas A&M, taken from every person born since 2002.

The new law, which TCRP helped negotiate, requires the department to present a detailed written disclosure form at time of birth, giving the parent the opportunity to opt out of the program, either at that time or within 60 days thereafter.

The new law also permits any adults to withdraw consent and have their sample destroyed, even if the parent had given consent. Nor may the department make any use of information or data taken from the sample, if destruction of the sample is requested.

The law puts into place rigorous privacy and confidentiality standards and assures that testing and research will be done consistent with accepted professional medical research methodologies.

Finally, it sets up an interim House of Representatives committee to study the application of the new law and make recommendations to the next session of the Legislature in 2011.

Jim Harrington, TCRP Director and attorney who represents the plaintiffs, called the new law “a great step that helps both scientific research but respects the privacy of people who do not wish to participate. It strikes an acceptable balance between medical science and individual liberty, and we are very pleased that the legislature responded so positively and so quickly to our lawsuit.”

According to Harrington, the only issue remaining in the lawsuit is what to do with the 4 million blood samples collected without consent, which the plaintiffs claim violates the constitutional right to be free from unlawful search and seizure and fundamental privacy rights. Harrington said the plaintiffs are negotiating with the department at this time, but expects that the federal judge in the case ultimately will have to make the decision.

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The Texas Civil Rights Project, a nonprofit foundation, promotes civil rights and economic and racial justice throughout Texas.