

April 19, 2010

Newborn DNA Registries Raise Privacy Concerns

Written by Sarah McIntosh

Parents are expressing outrage after discovering through recent news reports that their newborns' DNA has been stored or even turned over to the Armed Forces lab to build a national registry, without obtaining their consent.

It is not unusual for infants' DNA, obtained either via neonatal methods or soon after birth, to be tested for potential genetic problems. Several states store each new baby's DNA and may even turn it over for research purposes. But these facts are not widely known, and the reports raised concerns about the privacy of health information.

State, National DNA Registries

A February report in the Texas Tribune revealed the Department of State Health Services was giving hundreds of infant blood spots to the Armed Forces DNA Identification Laboratory (AFDIL). According to information obtained through open records requests, AFDIL was in the process of building a national mitochondrial DNA registry.

According to Twila Brase, president of the Citizens' Council on Health Care, a Minnesota-based nonprofit, five states keep these DNA samples indefinitely, and other states store DNA for as many as twenty-seven years.

"State health departments are storing the genetic test results. These are essentially state genetic registries," Brase said.

No Parental Consent Required

According to Brase, federal legislation is encouraging states to retain infants' DNA.

"The Newborn Screening Saves Lives Act of 2007 pushes more states toward retention of baby DNA," Brase said. "States that comply with standards issued by the Federal Advisory Committee on Heritable Conditions will receive federal funds. An August 2009 report does not recommend [that states obtain] parent consent. It recommends looking at the utility of parent consent sometime in the future."

If newborn DNA is sequenced into a numerical format, the government will have and own each child's complete genetic code, Brase notes.

"This knowledge will allow them to make all manner of inferences about the future medical conditions of the child and any offspring of the child," said Brase.

Francis Collins, current head of the National Institutes of Health and former head of the human genome project, said in remarks in October 2009 at the American Association for the Advancement of Science, "Whether you like it or not, a complete sequencing of newborns is not far away."

Privacy Rights Violations

Devon Herrick, a senior fellow at the National Center for Policy Analysis in Dallas, Texas, said whole-genome sequencing could become a de facto national identification card.

“Many people are willingly having their children’s DNA collected as a precaution against an unforeseen event such as a child abduction. However, the key is those cases are voluntary,” Herrick said. “Any state that collects a baby’s DNA should either dispose of the sample when [finished using it] or seek the parents’ permission to retain it for a fixed amount of time.”

Brase claims the Minnesota Department of Health has refused to allow parents to opt out, ignoring state genetic privacy law requiring consent.

“For three years, they have tried to exempt the program from law, without success. They continue to store and conduct research without consent. As a result, nine families have sued the state,” Brase said. “In Texas, a judge recently required the state to destroy the stored DNA of 5.3 million newborns in response to a Fourth Amendment lawsuit.”

Privacy Dangers

Storage of this genetic data creates several privacy concerns, Brase says.

“Government ownership enables the state health department and future legislatures to use newborn DNA as they see fit,” Brase said. “There is a potential for eugenic strategies, especially in this era of cost containment. Governments and legislatures could implement policies that use the genetic screening data to reduce the bearing of children with costly medical conditions, mandating the kind of decisions you’ve seen with Down’s Syndrome

children.” Brase says states are conducting their own research and sharing DNA with outside researchers without parents’ consent.

“The only real reason to store newborn DNA long-term is to conduct genetic research,” Brase said. “Every American child will grow into an adult whose DNA is owned and accessible to the government for research, law enforcement, predictive analysis, and social and genetic engineering. Most parents have no idea of this.”

Numerous Rights Violations

Some states are considering ways to prevent abuse of this genetic information. Oklahoma State Senator Jonathan Nicols (R-Norman) recently introduced SB 1250, which would ban the unauthorized use of infant DNA in his state.

“The very best action,” suggests Brase, “would be to take newborn screening out of state health departments. Newborn screening should be a hospital procedure, not a government procedure. If states never get the blood, they would never be able to store it, use it, or share it.”

Brase says parents should demand the state require explicit, informed, written consent for collection and retention of DNA, and that all clinics, hospitals, and birthing centers be required to discuss these options before a child’s delivery.

“This means opt-in, not opt-out. The consent form should include information on not only the benefits of retention and research but also the risks,” Brase said. “When the government owns your genetic code, they own who you are. Government storage of newborns’ DNA and genetic test results without parental consent violates genetic privacy rights, parents’ rights, patients’ rights, property rights, and Fourth Amendment constitutional rights.”