Government Warehousing of DNA a Disturbing State Secret

Citizens’ Council for Health Freedom Says Consent Is Critical, but Missing Factor

ST. PAUL, Minn.—As parents happily hold their newborn babies and dream of watching them grow up, the government is silently storing their DNA for use in research and analysis, all without parental consent.

Citizens’ Council for Health Freedom (CCHF, www.cchfreedom.org), a Minnesota-based national organization dedicated to preserving patient-centered health care and protecting patient and privacy rights, says such storage represents a severe violation of privacy and property rights.

“While there is little disagreement over the value of newborn screening, what happens after the screening is causing a contentious debate nationwide,” CCHF President and Co-Founder Twila Brase wrote recently for GeneWatch, a publication of the Council for Responsible Genetics. “At issue is whether state government officials are permitted to automatically keep the DNA and genetic test results of every newborn or whether parents must be asked before the child's genetic information is stored, used, and shared for analysis, research and other state government purposes.”

CCHF believes firmly that storage and research of newborn DNA should be allowed to occur only with the active consent of parents, rather than with an assumption of consent unless parents “opt-out.”

“Government storage and use of newborn DNA remains essentially a state secret. The public does not know,” Brase continued. “At last count, 18 states keep newborn DNA samples 10 years to indefinitely. In 2009, the federal government awarded a contract to the American College of Medical Genetics to develop a National Newborn Screening Translational Research Network to, among other things, create a physical or virtual repository of newborn DNA ‘stored by state newborn screening programs and other resources.’ Currently four states participate in a virtual repository, or as the URL notes, a ‘tissuelocator’: California, Iowa, Michigan and New York.”
“In addition, PEDIATRICS reports that 18 states have not addressed the retention and use of newborn DNA. Four states claim the child's DNA as state government property. Only three states require parents to be told they can opt-out of the DNA storage and use program, and only five states actually let parents request the destruction of the stored bloodspots.”

The U.S. House of Representatives will soon be considering legislation – the Newborn Screening Saves Lives Reauthorization Act of 2013 – which has no requirement that states obtain parental consent prior to storing newborn DNA.

Celebrating its 20th year, Citizens’ Council for Health Freedom is a patient-centered national health freedom organization based in St. Paul, Minn. CCHF supports patient and doctor freedom, medical innovation and the right of citizens to a confidential patient-doctor relationship. CCHF also sponsors the daily, 60-second radio feature, Health Freedom Minute, which airs on more than 150 stations nationwide on the American Family Radio Network and 90-plus stations on the Bott Radio Network. Listeners can learn more about the agenda behind proposed health care initiatives and steps they can take to protect their health care choices, rights and privacy.

CCHF president and co-founder Twila Brase, R.N., has been called one of the “100 Most Powerful People in Health Care” and one of “Minnesota’s 100 Most Influential Health Care Leaders.” Brase, a public health nurse, has been interviewed by CNN, Fox News, Minnesota Public Radio, NBC Nightly News, NBC’s Today Show, NPR, New York Public Radio, the Associated Press, Modern Healthcare, TIME, The Wall Street Journal, The Washington Post and The Washington Times, among others. She is at the forefront of informing the public of crucial health issues, such as intrusive wellness and prevention initiatives in Obamacare, patient privacy, informed consent, the dangers of “evidence-based medicine” and the implications of state and federal health care reform.

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