***NEWS RELEASE***

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**CCHF Alerts Parents About Government Storage and Use of Their Baby’s DNA**

**Citizens’ Council for Health Freedom Sends 9,700 Letters to Parents of New Babies, Urging Them to Opt Out of DNA Storage**

ST. PAUL, Minn.—Citizens’ Council for Health Freedom (CCHF, www.cchfreedom.org) wants parents of newborns in Minnesota to know that they aren’t the only ones who know their babies intimately.

Two weeks ago, CCHF, a Minnesota-based national organization dedicated to preserving patient-centered health care and protecting patient and privacy rights, sent letters to about 9,700 parents of babies born in August and September 2014 to inform them that their baby’s DNA was stored without their consent by the Minnesota Department of Health after blood spots were taken for newborn genetic screening tests performed in the hospital.

The letter continued, “According to a controversial 2014 law, it can also be used and shared. Unless you object. As a part of our ‘Protect Baby DNA’ project, we have enclosed the official state opt-out form, an envelope addressed directly to the state health department, and another envelope to send to our office to let us know you opted out.”

The state’s official opt-out form will tell the state to discard and not use the DNA of their baby.

“Already since our mailing,” said Brase, “We’ve heard from irate parents who had no idea that this was happening—no idea that their baby’s genetic blueprint was being stored and used by the government.”

In 2009, CCHF helped nine families sue the state health department for the storage, use and sharing of newborn DNA without parent consent. The families won on Nov. 16, 2011, and as a result almost all newborn DNA and newborn genetic screening test results stored since July 1, 1986, were discarded. A loophole to the Minnesota Supreme Court ruling, however, was found in the Minnesota Genetic Privacy Act, and the 2014 legislature repealed parent consent requirements. Thus, all Minnesota babies born on or after Aug. 1, 2014 have had their DNA stored without parent consent. The 2014 law also allows it to be used and shared for genetic studies and other purposes without parent consent.

“Baby DNA could even be sequenced, meaning a baby’s genetic code could be completely detailed and mapped—and then recorded in a state government database, used and shared,” Brase added.

CCHF also shared with parents the following issues of government storage and use:

- **Ownership:** The state couldn’t keep a child’s bike like they keep their DNA. Consent requirements mean ownership claims. But now, only if parents object will the state release ownership claims to baby DNA.
• **Law Enforcement:** If parents allow their baby’s DNA to remain in the hands of state officials, future legislatures could establish a state DNA registry of every citizen for law enforcement and other purposes. Texas parents, for example, sued when they discovered the state health department had given newborn DNA to the U.S. military to create a database for law enforcement.

• **Illegal for Adults:** Government cannot take or store DNA from an adult without consent unless a crime is committed. But state government officials are storing the DNA of every child after newborn screening is done.

• **Research Subject:** Without consent, the law allows research to be conducted on children, potentially including the full sequencing of the child’s DNA. While many people support research, it can be objectionable. One study found nearly 72 percent of parents want parent consent requirements before their child’s DNA is used for research.

• **Unwanted Discoveries:** The child's DNA contains genetic information about the mother and paternity information about the father. What will state officials or researchers discover about you or your child that you never agreed to let them find or look for?

• **What Will Your Child Want?** The DNA contains information on genetic weaknesses and possible future adult physical and mental conditions. Some claim there’s a crime gene, and many people do not want to know what their DNA says or to let others analyze it. Furthermore, how will children, as future adults, feel knowing the government stored their DNA without consent and have been using and sharing it for unknown purposes?

• **All DNA is Identifiable:** Government officials admit, and studies show, that people can be identified through their unique DNA.

In December, the U.S. House of Representatives unanimously passed “Newborn Screening Saves Lives Reauthorization Act of 2014” (H.R. 1281), which included an amendment, crafted with the assistance of CCHF, that requires that parents give informed consent before their babies’ DNA can be used for federally funded research. The law takes effect 90 days after enactment—or this month—but until then, Brase said, newborn blood spots will still be subject to research, and parents will not legally have to be informed about how their baby’s DNA is used.

The U.S. Senate also passed the bill in December, and President Obama signed it into law on December 18, 2014. The law stipulates, however, that parents give consent only related to federally funded research. There is still no consent required for government storage of DNA.

In its letter to Minnesota parents, CCHF also directed them to learn more at the organization’s special Baby DNA web site: www.ItsMyDNA.org.

For more information about CCHF, visit its web site at www.cchfreedom.org, its Facebook page at www.facebook.com/cchfreedom or its Twitter feed @TwilaBrase.

*Citizens’ Council for Health Freedom* is a patient-centered national health freedom organization based in St. Paul, Minn., that works to protect health care choices and patient privacy. CCHF sponsors the daily, 60-second radio feature, Health Freedom Minute, which airs on approximately 350 stations nationwide, including 200 on the American Family Radio Network and 100 on the Bott Radio Network. Listeners can learn more about the agenda behind health care initiatives and steps they can take to protect their health care choices, rights and privacy.

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