



BABY DNA UPDATE - MN  
May 9, 2012

## Bill with Consent Protections for Baby DNA Heads to Minnesota Governor

A "newborn screening" amendment was attached to an unrelated bill (HF 2967 - **Holberg**) on Monday, May 7, 2012. Prior to the amendment being added, CCHF worked with Rep. Holberg and other legislators to make sure certain informed parent consent requirements and strongly-worded protections regarding newborn citizens and Baby DNA were added to the amendment.

HF 2967, with the revised amendment, is now headed to Minnesota Governor Mark Dayton for his signature. [To read the language, see Article 4.](#)

### CONSENT REQUIRED:

The amendment establishes various detailed requirements related to written *informed* parent consent for state government storage and use of Baby DNA.

**NOTE:** to address one of CCHF's longstanding concerns, the MN Department of Health (MDH) says they will not seek consent for storage and use of Baby DNA at the time when the baby's heel is pricked for the newborn screening test (24 to 48 hrs after birth when parents are exhausted and vulnerable to signing any paper put in front of them). Instead, they will seek consent in pre-natal classes and at doctor's offices. If they do try to get consent when you're in the hospital with your newborn baby, please let us know!

### NO EXEMPTION:

CCHF worked long and hard to make sure the amendment (now part of the Holberg bill) explicitly declares that NOTHING will exempt MDH from the requirements of the MN Genetic Privacy Act and its financial penalties for violations of the Act. These penalties allowed nine families to successfully sue MDH all the way to the MN Supreme Court, which ruled that the State of Minnesota and the Commissioner of Health were in violation of the Act.

### NEW PROTECTIONS:

During negotiations over the language, CCHF also made sure that the amendment included the following requirements and protections:

- A "[Tennessee Warning](#)" about state government data requests must be *attached* to the parent consent form;
- MDH must tell parents on the consent form that their child's blood sample *contains DNA*;

- The consent form must inform parents about the *risks* of government storage and use; and
- MDH is prohibited from conducting research, public health studies, or new test development within "newborn screening program operations" (which are and can be done without consent unless parents object to the screening).

#### **DESTRUCTION ANNOUNCEMENT:**

Also, at CCHF's suggestion, language was added to require MDH officials to make a public announcement when all Baby DNA and genetic test results stored prior to the November 16, 2011 MN Supreme Court ruling are destroyed. This destruction -- and the Department's announcement -- will not occur until after the pending class action lawsuits have been settled.

#### **ETERNAL VIGILANCE:**

After CCHF's 8-year battle over Baby DNA, we do not expect the MN Department of Health to stop trying to skirt or undo the state genetic privacy law. Eternal vigilance is needed. This session MDH tried in *three* different ways to exempt themselves from the MN Genetic Privacy Act (MGPA) — for example, they tried to exempt biological specimens from the definition of "genetic information" — but we discovered these attempts, made them known to concerned legislators and successfully opposed them.

#### **ACCOUNTABLE:**

These new requirements and protections, amended onto bills by **Sen. David Hann** (R-Eden Prairie) and **Rep. Mary Liz Holberg** (R-Lakeville), will put some clearly defined legal parameters around state government access to Baby DNA — and they will keep state health officials accountable to Minnesota's strong Genetic Privacy Act and liable for serious sanctions if violations occur.

*Thank you to all who helped to protect the genetic privacy and  
DNA property rights of newborn citizens!*