Baby DNA Bill to End Genetic Privacy
HF2526 (Norton)/SF2047(Marty) “Newborn Screening Modifications”

This bill undermines the Nov. 2011 MN Supreme Court decision on parent control over newborn genetic information, and the consequent 2012 amendments to require parent consent. The focus of this bill is not newborn screening; it’s on what happens to the child’s DNA and genetic test results post-screening.

WHAT THE BILL DOES:

1) **Gives state government first dibs to newborn DNA and genetic test results.**
   
   The bill repeals today’s opt-in (parent consent requirements) and changes to an opt-out (dissent) system. If parents figure it out at delivery or afterward, the burden is on them to protect their child. Today, because of consent requirements, state government can only screen and short-term store without the parent’s signed written informed permission slip. This bill repeals today’s parent consent requirements and allows government to store and use baby DNA and genetic test results forever.

2) **Will harm newborn screening and potentially newborn health.**
   
   The public is already losing trust in government newborn screening. Beginning in 2003, as more MN parents discovered the state’s DNA storage, they opted out of the screening. In 2003 two parents refused. In 2008, 89 parents refused.

3) **Allows genetic research on children -- without parent consent.**
   
   Newborn screening has been called “the first program of populationwide genetic testing.” (American Journal of Public Health). This bill repeals parent consent for newborn screening studies, even though newborn screening studies and test development are genetic research for a genetic program. Today, use of the child’s genome for such research and test development requires written parent consent.

4) **Would permit analysis of the child’s DNA**
   
   Nothing in the bill prohibits the Health Department or their contractors from using the child’s bloodspots to conduct DNA analysis as part of newborn screening studies and test development. This could include looking for biomarkers for childhood leukemia, autism and diabetes. A Univ of Mich study found 71.8% of parents would refuse any research without parent consent.

5) **Does not prohibit full Genomic Sequencing as part of NBS research**
   
   The federal government has provided $25 million to create genomic sequencing for newborn screening, which would put every child’s genetic code on record with the government.