

## Minnesota Legislators Attempt to Eliminate the Genetic Privacy Rights of Newborn Citizens and Their Parents

*HF 1341 as Introduced – Rep. Paul Thissen (D-Mpls.)*

**History:** On August 1, 2006, the Minnesota Genetic Privacy Law went into effect. The law requires informed written consent for the collection, storage, use and dissemination of genetic information. The Minnesota Department of Health (MDH) has rigorously refused to comply with the law. In March 2007, a state administrative law judge ruled that MDH is violating the genetic privacy law in the implementation of the state's newborn (genetic) screening program. The health commissioner appealed the ruling, and lost the appeal. During the 2007 and 2008 legislative sessions, MDH also attempted to exempt the newborn screening program from the genetic privacy law's consent protections. In 2007, the language was not accepted. In 2008, the bill was vetoed. MDH has continued to illegally collect, store, use and disseminate newborn blood and baby DNA for various purposes, including genetic and DNA-based research.

On March 4, 2009, HF 1341 was introduced. The bill will attempt to exempt newborns (and their parents) from the consent requirements of the genetic privacy law. Specific concerns include:

- **Elimination of Genetic Privacy Rights into the Future.** HF 1341 seeks to exempt “the Department of Health’s collection, storage, use, and dissemination of genetic information and blood specimens for testing infants” from the state’s genetic privacy law (p. 1, lines 21-24). All children born on or after July 1, 1997—the day MDH began warehousing baby DNA—will not have their genetic privacy protected by the state genetic privacy law.
- **Eliminate Strong Legal Protections.** By exempting the newborn genetic testing program from the strong legal protections of the Government Data Practices Act (Chapter 13), HF 1341 seeks to limit options for legal redress for harms suffered, including future illegal actions by MDH. Genetic information collected by government becomes government data. It therefore belong in the Government Data Practices Act. (p. 1, lines 21-24)
- **Elimination of Consent Protections.** HF 1341 seeks to repeal the parent signature requirement (consent) and adds a signature requirement for hospital staff (dissent). (p. 2, line 33)
- **Retain Illegal DNA Warehouse.** HF 1341 does not specifically require the health department to dismantle their current illegal baby DNA warehouse of now more than 819,282 newborn blood and DNA specimens – all stored without parent consent.
- **Creates Genetic Database.** HF 1341 seeks to establish in law a state government database of newborn genetic test results. Today, despite no law authorizing the databasing of test results, there are more than 1.5 million children in the database. Minnesota law only requires MDH to keep a registry of the children with positive testing results, not all the children tested. (p. 4, line 21)
- **Backdoor Authority.** Authorize in law the Department of Health’s current—but illegal—“storage, use, and dissemination of genetic information and blood specimens.” – today, there is no authority in law to store, use or disseminate newborn blood and DNA. State law only authorizes newborn genetic testing. By including these specific words in the exemption language, backdoor authority to collect, store, use and disseminate for purposes beyond the testing will be authorized. (p. 1, lines 21-24)

**Conclusion:** HF 1341 will undo genetic privacy rights and legal rights under state law. Current Minnesota law (M.S. 13.386) protects children and families with informed consent requirements and legal options. Current informed written consent requirements in Chapter 13 of Minnesota law should be retained, and MDH should be sanctioned for ongoing violation of the privacy rights of citizens.

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