

MN Dept. of Health is Violating State Privacy Law; Asks Legislature to Legalize their Violations!

MDH wants Minnesota legislature to approve ongoing illegal storage of —and research on—baby DNA and newborn genetic test results without written parent consent.

HF1341 (Thissen) / SF1478 (Scheid) will:

- Legalize years of **illegal** storage and genetic research activities of MDH.
- Eliminate today's informed written consent requirements for MDH/Mayo Clinic storage of and research using genetic test results, newborn blood and baby DNA.
- Remove the state's largest genetic testing program from the strong legal protections of the Minnesota genetic privacy law, including legal redress.
- Eliminate genetic privacy rights for all children born after July 1, 1986.
- Remove government-held genetic data from the strong legal protections of the Minnesota Government Data Practices Act, including the genetic privacy law.
- Exclude newborn blood—baby DNA—from definition of 'genetic information' *allowing, and setting a precedent for, DNA extraction/analysis without consent.*
- Retain the illegally established MDH and Mayo Clinic warehouses of baby DNA.

Key History:

- July 1, 1986 – Minnesota Department of Health (MDH) begins to store newborn genetic test results in state database without statutory authority or parent consent.
- July 1, 1997 – MDH also begins to warehouse newborn blood and baby DNA.
- 2004 - MDH's \$6.9 million contract with Mayo Clinic also allows Mayo to store baby DNA and test results—and to conduct research without parent consent.
- **Aug. 1, 2006 – Minnesota Genetic Privacy Law (M.S. 13.386) takes effect.**
- March 23, 2007 – Administrative Law Judge rules that MDH is violating the law by storing, using and disseminating newborn blood and baby DNA to researchers.
- **July 3, 2007 – Chief Administrative Law Judge agrees with ALJ and strikes down MDH's appeal of ALJ decision. Requires written informed consent.**
- May 19, 2008 – MDH legislation to exempt MDH's collection, storage, use, and dissemination of newborn blood and DNA from the informed written consent requirements of the 2006 MN Genetic Privacy Law is vetoed.
- 12/31/08 – DNA of 819,282 children & test results of 1.5 million children stored.
- More than 52,519+ children have been involuntary subjects of genetic research.
- **March 11, 2009 – Nine families sue MDH in Hennepin County Court.**
- **March 16, 2009 – MDH testifies that “ZERO” parents have given consent.**

Protect Baby DNA - Say NO to HF 1341/SF1478