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.
- 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.
- 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