

Newborn Genetic Testing – What Minnesota Parents Need to Know

2003 MN Law: Parents may refuse testing for their baby

- Newborn genetic testing is **not required** by law – if parents express their objection in writing.
- Hospitals, doctors, midwives and others must advise parents of the following:
 - That the blood or tissue samples used to perform testing as well as the results of such testing may be retained by the Minnesota Department of Health (MDH).
 - The benefit of retaining the blood or tissue sample.
 - That the following options are available to parents with respect to the testing:
 - i) Parents may decline to have the tests, or
 - ii) Parents may elect to have the tests but to require that all blood samples and records of test results be destroyed within 24 months of the testing.
- Parents and guardians who refuse testing, or elect for testing and later destruction of blood samples, must do so on a form that is signed by the parent or legal guardian and made part of the child's medical record. A written objection exempts babies from blood testing requirements.
- **If a parent does not sign the form**, the newborn baby's blood will be drawn, sent to the State, and tested. The results of the testing will be provided to the child's physician and kept in a state database. The blood specimen (dried blood spots) will be kept, possibly for future uses.

Since the 2003 Minnesota legislation requires parents to be informed only of the benefits of genetic testing, consider a few of the concerns:

- Blood spots, from heel sticks taken after birth, contain the baby's DNA – genetic code.
- Blood spots at the State are considered *state property*. The MDH formerly kept blood spots for only 5 years, but the policy recently changed. Blood spots are now kept indefinitely. Approximately 70,000 new babies are born each year. MDH currently has the blood spots (DNA) of 350,000 citizens.
- Laws can change. As technology advances and genetic testing and biometric identifiers becomes more common, the legislature may decide to expand use of its DNA collection.
- A state database will hold the names, information and results of genetic testing.
- There is no law to prevent future state testing for predisposition to cancer or Alzheimer's or mental illness. Without specific legislative approval, the law allows the Minnesota Health Department to expand the number of disorders for which babies will be tested.
- The law does not forbid researcher access to DNA-laden blood spots. Researchers have already made requests for access to blood spots held by the health department.
- Should parents decide to genetically test their children? How will their children feel when they become adults and find that their genetic profile may be known by the State?

Important Additional Information

- Always consult with your doctor on testing decisions. Of the 32 disorders for which the State will test, one can cause mental retardation within weeks of birth: phenylketonuria (PKU).
- **Parents may choose to have testing done by a private institution** (not by the State).
- The Minnesota Department of Health (MDH) charges hospitals \$61.00 for each child tested.
- MDH has received a \$75,000 federal grant to develop a "State Genetics Plan for Minnesota."