SF 3344 (Sen. Linda Scheid)
Informed Consent for Newborn Genetic Testing

Selected language from Section 2 of the 4-section bill,
as introduced on March 20, 2006.

On March 31, 2006, the Senate Judiciary Committee, chaired by Sen. Don Betzold, voted to delete the entire section below from the bill. This means that the stricken section (current law) stands and the underscored section (informed consent required before testing) was eliminated from the bill.

BILL KEY: stricken = removed; old language. underscored = added; new language

Sec. 2. Minnesota Statutes 2004, section 144.125, subdivision 3, is amended to read:

Subd. 3. Objection of parents to test. Persons with a duty to perform testing under subdivision 1 shall advise parents of infants (1) that the blood or tissue samples used to perform testing thereunder as well as the results of such testing may be retained by the Department of Health, (2) the benefit of retaining the blood or tissue sample, and (3) that the following options are available to them with respect to the testing: (i) to decline to have the tests, or (ii) to 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. If the parents of an infant object in writing to testing for heritable and congenital disorders or elect to require that blood samples and test results be destroyed, the objection or election shall be recorded on a form that is signed by a parent or legal guardian and made part of the infant’s medical record. A written objection exempts an infant from the requirements of this section and section 144.128.

(a) Persons with a duty to perform testing under subdivision 1, shall request the parent’s consent before performing testing, provide parents with a form to direct the state to dispose of test results and blood specimens, and offer parents private testing options. Parents must be advised in a form separate from the consent form:

1. that the parents are not legally required to consent to any testing;
2. that the testing is genetic testing;
3. that the blood or tissue samples used to perform testing thereunder as well as the results of such testing may be retained by the Department of Health;
4. the benefit of retaining the blood or tissue sample;
5. the concerns related to genetic testing and data banking of DNA samples;
6. that retained blood specimens may be made available for medical and genetic research; and
7. that the following options are available to them if they choose to have the testing:
   i. PKU only as performed by the commissioner
   ii. Full roster of genetic tests as performed by the commissioner
   iii. Private, nonstate testing options;
   iv. Consenting or refusing consent to use of test results in medical or genetic research; or
   v. To elect to have the tests done by the state but to require that all blood samples and records of test results be destroyed within 30 days of the testing or of receipt of a parent’s direction to destroy blood samples and records of test results, whichever is later.