

HOUSE RESEARCH

Bill Summary

FILE NUMBER: H.F. 3387

DATE: March 23, 2006

Version: As introduced

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Subject: Newborn Screening Modifications

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Overview

This bill modifies the existing newborn screening process by: requiring legislative approval prior to updating the list of tests performed; strengthening the parental consent and information requirements; and providing a form and updated process for requesting the destruction of test samples and results.

Section

- 1 **Determination of tests to be administered.** Amends § 144.125, subd. 2. Requires the commissioner of health to receive authorization from the legislature before revising the list of tests performed on newborns to determine the presence of heritable or congenital disorders.
- 2 **Objection of parents to test.** Amends § 144.125, subd. 3. Requires that those performing newborn testing obtain the consent of parents and prescribes the form of and information to be included on the consent form.

Requires that parents be advised in a separate form, that: (1) they are not legally required to consent to any testing; (2) the testing is genetic testing; (3) the blood or tissue samples and results of the testing may be retained by the Department of Health; (4) the benefit of retaining the samples; (5) the concerns related to genetic testing and the data banking of DNA samples; (6) samples may be available for medical and genetic research; and (7) the following testing options are available: PKU only testing; full roster of genetic testing; private/non-state testing; consenting or refusing to consent to the use of the test results in medical or genetic research; electing to have all blood samples and records destroyed within

Section

30 days of the test or receipt of parental destruction directive (established in section 3).

- 3** **Parental destruction directive.** Amends § 144.125 by adding subd. 4. Requires the commissioner of health to prepare a separate form for parents' use in requesting that blood samples and test records be destroyed 30 days after receipt of the form. Requires the form to be given to the parent of a newborn and include information about data practices and blood sample storage policies. Requires that the parent sign the form without requiring a witness or notary.
- 4** **Commissioner's duties.** Amends § 144.128. Adds to the commissioner of health's duties: providing testing results to parents; and providing a certificate of destruction to all parents electing to have test results and blood specimens destroyed.