

# HOUSE RESEARCH

## Bill Summary

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**Subject:** Newborn Genetic Testing

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### Overview

This bill provides that the Department of Health's newborn screening program is not subject to the general genetic information provision of the data practices act, and establishes new requirements for informing parents about the screening process and options related to the collection and use of their infants' genetic data.

#### Section

- 1 Genetic information; data practices.** Provides that the Department of Health's newborn screening program is not governed by the general genetic information provisions of the data practices act, which require written, informed consent of an individual prior to the collection of genetic information, and prohibit use of the information for purposes other than those for which the individual has provided written, informed consent.
- 2 Objection of parents to test.** Requires that parents or guardians be provided with a written document providing information about the genetic testing, and specifying the options available to the parent or guardian, including a new option for the parent or guardian to decline to have the test results and samples used for public health studies and research. The document must also inform parents or guardians of their right to object to the testing.
- 3 Newborn screening report.** A definition of "public health studies and research" is provided. Requires the Department of Health to submit a report and make recommendations to the legislature by January 15, 2009, regarding its efforts relating

**Section**

to enhancing and ensuring parents are fully informed about the newborn screening program, and their rights and options related to testing, storage, public health practices, studies and research, the ability to opt-out of the process, and the ability to seek private testing.