

# Newborn Screening Program

HF 1341 / SF 1478

## Newborn Screening Program

Since 1965, the Minnesota Department of Health (MDH) has assured that all babies born in Minnesota have access to screening and that babies with any of the conditions are linked quickly with needed care. Shortly after birth, **approximately 73,000 infants each year are screened for 54 rare and serious medical conditions** including hearing loss. If not detected and treated early, these conditions can lead to chronic illness, physical disability, mental retardation, developmental problems, or infant death.

## Newborn Screening Advisory Committee

Established in statute, the Newborn Screening (NBS) Advisory Committee makes recommendations to the Commissioner of the Minnesota Department of Health (MDH) regarding the addition of newborn screening tests. The NBS Advisory Committee includes parents of affected children, primary care physicians, genetic and metabolic specialists, as well as advocacy groups such as the March of Dimes.

## Newborn Screening Partners

MDH works in partnership with a variety of health care providers throughout the state to assure that all babies have access to screening, parents have information about newborn screening, and that babies with any of the conditions are linked quickly with needed care. These partners include:

- Hospitals and laboratories,
- Specialists at the University of Minnesota, Children's Hospital and Clinics of Minnesota,
- Mayo Medical Laboratories,
- Minnesota Hospital Association, March of Dimes, Minnesota Medical Association, and the Minnesota Chapter of the American Academy of Pediatrics.

## Background

The newborn screening statute M.S. § 144.125 **requires that all infants be tested for rare and serious conditions**. Clarification is needed to specify that M.S. §§ 144.125 to 144.128 governs MDH's collection, storage, use, and dissemination of genetic information and specimens for testing infants for heritable and congenital disorders. Passed in 2006, the genetic privacy statute M.S. § 13.386 specifies that collection, storage, use, and dissemination of genetic information may be used only for the purposes to which an individual has provided written informed consent, and may only be stored for a period of time indicated in that consent.

During the 2008 legislative session, the MDH proposed a bill to clarify M.S. §§ 144.125 to 144.128 governs the Newborn Screening program and to resolve other issues outlined in this proposal. Ultimately the legislation was vetoed by the Governor. In his May 2008 veto message, the Governor stated concerns about the storage of newborn blood samples, and the use of those samples for non-screening research without parental consent. This proposal addresses these concerns.

## Proposed Statutory Changes

**Clarify that M.S. §§ 144.125 to 144.128 govern MDH's collection, storage, use, and dissemination of genetic information and specimens for testing infants for heritable and congenital disorders.**

## Describe newborn screening program operations to include:

- The use of residual samples for quality control, quality assurance, and new test development,
- The destruction of all samples within 25 months of the month of birth, unless a parent or legal guardian has given written informed consent to retain the sample.



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**Provide parents with additional options,** including the right to have the tests performed, but decline having the test results and samples used for newborn screening program operations.

**Require that parents are provided with information about newborn screening prior to collecting a sample,** including: what data may be collected as the result of testing and how samples and data will be stored and utilized; alternatives available to the parents; the benefits of testing and retaining the blood samples; and the MDH Web site address.

**Require MDH to report to the Legislature** on efforts to ensure that parents of newborns are fully informed about the newborn screening program and of their rights and options regarding newborn screening.

## **MDH Efforts to Inform Parents of Newborn Screening**

### **Provider Education**

Laboratory directors, nursery managers, and other health care providers across the state play a major role in educating parents about newborn screening. MDH provides these health care providers with information regarding their responsibilities to educate parents of newborns about the benefits of screening as well as parental options. In addition, MDH works with the Minnesota Hospital Association (MHA) to educate hospitals staff concerning the importance of educating parents about their options.

### **Parent Education**

MDH has one of the most active parent education programs in the country. Our goal is to provide parents with information needed to make informed choices regarding newborn screening.

### **“One Simple Test” Brochure**

In partnership with laboratory directors, nursery managers, and other health care providers, parents are provided the “One Simple Test” brochure which describes the lifesaving benefits of screening, provides information on the newborn screening process, and outlines parental options including the ability to refuse testing and to request specimen and records destruction.

## **Newborn Screening Web site**

[www.health.state.mn.us/newbornscreening](http://www.health.state.mn.us/newbornscreening)

The Newborn Screening Web site has been revised to ensure that parents and providers can readily find information about the benefits of newborn screening. The updated Web site provides easy access to fact sheets and forms, including parent opt-out forms. A new “Screening Spotlight” section has been added to provide families and health care professionals the opportunity to share their real-life stories about the benefits of newborn screening.

## **Prenatal Parent Information**

MDH is working to develop effective ways to provide information about newborn screening to expectant parents. Working in partnership with prenatal care providers, hospitals, and parents, MDH is evaluating options for communicating with expectant parents during the prenatal stage.

## **Questions or Comments?**

If you have questions or comments about the Newborn Screening Program or this legislation, contact Mark McCann, manager of the Newborn Screening Program, at (651) 201-5450 or [Mark.McCann@state.mn.us](mailto:Mark.McCann@state.mn.us)

## **Learn More**

To learn more, visit our Newborn Screening Program Web site:

[www.health.state.mn.us/newbornscreening](http://www.health.state.mn.us/newbornscreening)