

The Minnesota Newborn Screening Programs

The Minnesota Newborn Screening Programs are public health programs through which all infants born in the state are screened soon after birth for a variety of disorders. The Newborn Screening Program, which uses blood spots to screen for more than 50 disorders, is governed by [Minnesota Statutes, sections 144.125 and 144.128](#). The Early Hearing Detection and Intervention program, through which infants are tested for hearing loss, is governed by [Minnesota Statutes, section 144.966](#). Screening for critical congenital heart disease (CCHD) is governed by [Minnesota Statutes, section 144.1251](#).

Infants are screened for more than 50 genetic disorders

Under the Newborn Screening Program, hospitals and others in charge of caring for newborn infants are required to take blood from newborn infants and submit the blood spots to the Minnesota Department of Health to be tested for heritable and congenital disorders. The Commissioner of Health determines the list of disorders for which infants are tested. Currently, MDH screens for more than 50 inherited and congenital disorders, including the following:

- amino acid disorders
- fatty acid oxidation disorders
- organic acid disorders
- endocrine disorders
- lysosomal disorders
- hemoglobinopathies

(For a full list of the disorders, see the MDH website, <http://www.health.state.mn.us/divs/phl/newborn/program/2018newbornscreeningpanel.pdf>)

Under this program, MDH duties include the following:

- making certain information and forms related to storage of blood samples and test results are available to health care providers and parents
- notifying newborns' primary care providers of the results of the screen
- making referrals for the necessary treatment of diagnosed cases of inherited and congenital disorders when treatment is indicated
- maintaining a registry of the cases of disorders detected for the purpose of follow-up services

Expansion of the program

The legislature has expanded the program in recent years. A law passed in 2007 required all hospitals to establish an Early Hearing Detection and Intervention (EHDI) program. In 2013, a law was enacted that required all hospitals to test newborns for critical congenital heart disease.

Parental consent to newborn screening is presumed unless parents object in writing

Generally, consent for newborn screening is presumed unless parents object to the screening in writing by specifying that they want their child to opt out of the screening. Parents are notified that they may opt out of the tests being performed or have the tests performed without the results stored.

Prior to collecting a blood sample, persons with a duty to perform testing under the Newborn Screening Program must inform parents of the following:

- the benefits of newborn screening
- that parents have the right to decline to have newborn screening performed and that they may secure private testing
- that the blood samples and test results may be stored by MDH unless the parents elect against storage
- that parents have the right to have the tests performed but not have the blood samples or test results stored
- that parents have the right to authorize, in writing, that results may be used for public health studies or research
- the MDH website where more information may be found

The state's handling of genetic information is governed by law

In 2006 a law was enacted governing the treatment of genetic information held by state government. [Minnesota Statutes, section 13.386](#), subdivision 3, requires that, unless provided in law, genetic information about an individual may be collected by the government with the written, informed consent of the individual. The genetic information may be used only for the purposes and stored for the period of time to which the individual consented. Also, the genetic information may be disseminated only with the individual's written, informed consent, or as necessary to accomplish the purposes of the collection.

In November 2011, the Minnesota Supreme Court ruled on this issue in *Bearder v. State of Minnesota* (806 N.W. 2d 766, November 16, 2011), which challenged certain MDH activities related to the newborn screening programs in light of the genetic privacy law ([Minn. Stat. § 13.386](#)). The state Supreme Court found that the genetic privacy law does generally apply to blood samples collected under the newborn screening program; however, there are narrow exceptions provided in statute that authorize MDH to administer the newborn screening tests of blood samples, record and report those test results, maintain a registry of positive cases, and store those test results as required by federal law.

In 2014, the newborn screening laws were amended to allow stored blood samples and tests results to be used for studies related to newborn screening, including studies used to develop new tests. The law prohibits use of the blood samples and test results for any other reason than allowed under the law without the written consent of the parent. The law also prohibits the sale of bloodspots, test results, or other data collected during the newborn screening process.

The law allows parents and a person who was tested under the newborn screening program, once that person is 18 years or older, to request that the person's blood samples and test results are destroyed. Once a parent or person who was tested requests the blood samples or test results be destroyed, the results must be destroyed within a certain time period, as provided in law.

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