MN HOUSE RESEARCH

The Minnesota Newborn Screening Program

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The Minnesota Newborn Screening Program is a public health program through which infants born in the state are screened soon after birth for certain health conditions. Blood spot screening, in which infants are screened for more than 60 inherited and congenital disorders, is governed by Minnesota Statutes, sections 144.125 and 144.128. Screening of infants for hearing loss is governed by Minnesota Statutes, section 144.966, and screening for critical congenital heart disease is governed by Minnesota Statutes, section 144.1251.

Program administration

The Minnesota Department of Health (MDH) administers the Newborn Screening Program at the state level. Under the program, newborns are screened for inherited and congenital disorders, hearing loss, and critical congenital heart disease (CCHD). The program is funded with fees that are set in statute. MDH duties under the program include the following:

- in consultation with the Newborn Screening Advisory Committee, establishing the list of inherited and congenital orders for which infants are screened
- communicating hearing loss and CCHD screening protocols or recommendations and providing training
- making screening program information and forms available to health care providers and parents
- screening infant blood samples for the panel of inherited and congenital conditions and notifying infants’ primary care providers and parents of the test results
- providing referrals for treatment when indicated and contracting with a nonprofit organization to provide support services to families of children with hearing loss
- maintaining a registry of disorders detected for the purpose of follow-up services

Infants are screened for more than 60 inherited and congenital disorders

Unless an infant’s parent opts out of screening, hospitals and others in charge of caring for newborn infants must take blood from newborn infants and submit the blood spots to MDH to be tested for inherited and congenital disorders. Currently, infants are screened for more than 60 disorders, including metabolic disorders, endocrine disorders, hemoglobin disorders, lysosomal storage disorders, and other specified disorders. For a full list of the disorders, see the MDH newborn screening panel at http://www.health.state.mn.us/people/newbornscreening/program/newbornscreeningpanel.pdf.

Screening for hearing loss and critical congenital heart disease

All hospitals must establish an early hearing detection and intervention program to test newborns for hearing loss and must inform the newborn’s parents, primary care provider, and MDH of the test results. Hospitals and other facilities that provide maternity and newborn care are also required to screen newborns for critical congenital heart disease using pulse oximetry screening and to report screening results to MDH.

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Parental consent to screening is presumed unless parents object in writing

Generally, consent for newborn screening is presumed unless parents opt out of the screening in writing. 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 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 test 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

Minnesota Statues, section 13.386, subdivision 3, provides that a government entity may collect genetic information about an individual only with the individual's written, informed consent, unless otherwise provided in law. 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 *Bearder v. State of Minnesota* (806 N.W.2d 766, 2011), the Minnesota Supreme Court ruled on a challenge to 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 test 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.

Parents or a person who was tested as a newborn under the newborn screening program, once that person is age 18 or older, may request that MDH destroy the person's blood samples and test results. If a parent or person who was tested requests the blood samples or test results be destroyed, the samples must be destroyed within 30 days after MDH receives the request, and results must be destroyed within the later of 30 days after MDH receives the request or the earliest time allowed under federal regulations.

For more information on the Newborn Screening Program, see the MDH website at https://www.health.state.mn.us/people/newbornscreening/index.html.

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