



Instructions for Birth Facilities Regarding Parental Newborn Screening Options

Newborn screening is an important, even life-saving, part of infant health care. Minnesota Statutes §144.125 Subd. 3 and §144.966 Subd. 3 provide several options to Minnesota parents and guardians regarding newborn screening. It also requires birth facilities and other healthcare providers to educate parents about specific benefits and risks associated with choosing the various options.

To offer the best care to the infants born in your facility and to inform parents of their rights under the law, the Minnesota Department of Health Newborn Screening Program recommends taking the following steps:

- ____ 1. Review the *One Simple Test Can Make a Difference for Your Child* brochure with parents. It is available free from the Newborn Screening Program and can be ordered by calling 651-201-5466 or 800-664-7772.
- ____ 2. Tell parents that their infant's newborn screening specimen and hearing screening results will be sent to the Minnesota Department of Health and that test results and the blood sample will be retained by the department.
- ____ 3. Tell parents about the benefits of keeping their infant's newborn screening specimen. See *Benefits of retaining newborn screening specimens* below.
- ____ 4. Tell parents that they can have their infant's newborn screening specimen and test results destroyed. See *Directive to Destroy Newborn Screening Test Results and/or Blood Sample* form for a list of associated risks.
- ____ 5. Inform parents that they can decline to have their infant screened. See *Risks of not screening a newborn* below.
- ____ 6. Tell parents that if they decline to have their infant screened, the choice will be recorded and documented in their infant's medical record and documented with the Minnesota Department of Health. See *Documenting a refusal of newborn screening* below.

Risks of not screening a newborn

Babies can die or become developmentally delayed as a result of not being screened. Children with the diseases screened for or with hearing loss often appear healthy at birth and may not display symptoms for days or weeks. By the time symptoms appear, damage can be irreversible. Therefore, an affected child not screened may not receive treatment needed to prevent developmental delay, illness, or death.

Benefits of retaining newborn screening specimens

Stored newborn screening specimens enable (a) continuous quality improvement of newborn screening; (b) evaluation and comparison of new testing methods; (b) epidemiological research (on anonymous specimens); (c) special health-related studies for specific patients or families; and (d) the identification of missing or deceased

children. Each of these activities benefits either public health or families of those from whom specimens are obtained.

Private testing

Parents may choose to have newborn screening performed by a private testing laboratory instead of by MDH.

The specific diseases screened for by private testing laboratories may vary from those screened for by the Minnesota Department of Health. Minnesota is a national leader in newborn screening and screens for all the diseases recommended for screening by the American College of Medical Genetics.

Private testing must be arranged by the parent or guardian through their doctor and a private testing laboratory.

Birth facility requirement associated with private testing option – If private testing is chosen, the birth facility must provide documentation to the Minnesota Department of Health that the parent or guardian refused to have their child screened by the Minnesota Department of Health.

Documenting a refusal of newborn screening

- ____1. Have the parent read and sign the *Parental Refusal of Newborn Screening* form. Have a witness from the birthing facility sign the form.
- ____2. Insert the original document in the child's medical record.
- ____3. Provide copies to the parent, the child's physician, and the Minnesota Department of Health Newborn Screening Program at the address below.

Documenting a directive to destroy newborn screening specimen and/or test results

- ____1. Have the parent read and sign the *Directive to Destroy Newborn Screening Test Results and/or Blood Sample* form. Have a birthing facility witness or a notary public sign the form (to authenticate parental identity).
- ____2. Insert the original document in the child's medical record.
- ____3. Provide copies to the parent, the child's physician, and the Minnesota Department of Health Newborn Screening Program at the address below.

Parental Refusal of Newborn Screening forms and *Directive to Destroy Newborn Screening Test Results and/or Blood Sample* forms are available at: <http://www.health.state.mn.us/newbornscreening>

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