



## **INSTRUCTIONS: Refusal of Newborn Blood Screening**

**Minnesota Department of Health  
Newborn Screening Program  
Public Health Laboratory  
Phone: (612)-676-5260  
Rev. 1/2003**

**In the event that parents ask about refusing the newborn blood spot screening for their child, please do the following:**

\_\_\_\_\_1. Review with parents the “Your Baby’s Newborn Screening” brochure. It is available at [www.health.state.mn.us/divs/fh/mcshn/nbs.htm](http://www.health.state.mn.us/divs/fh/mcshn/nbs.htm) or can be obtained by calling the number above. The brochure is updated regularly; please make sure each parent has the most recent version.

\_\_\_\_\_2. Review the benefits of Newborn Blood Screening and the risks of refusing this screening:

Benefits: Early identification of children with the diseases included in newborn screening provides an opportunity to start treatment before symptoms appear. Early treatment for these diseases can prevent mental retardation, severe illness and even death.

Risks of refusing: If parents choose not to have their child screened through the Minnesota Department of Health Newborn Screening Program, they risk that their child may have one of the diseases and will not receive the treatment necessary to prevent mental retardation, illness or death. These diseases usually occur without a family history. Children with these diseases often appear healthy at birth and may not have symptoms from the disease for days or weeks.

\_\_\_\_\_3. Inform parent about:

Data privacy protections: The Minnesota legislature classified newborn screening information as private data. Outside of the Minnesota Department of Health Newborn Screening Program, access to data from an individual is made available only to the patient/family and the medical provider(s) involved in the care of that child. Sharing of individually identifiable data requires a signed consent allowing the release of such data. Records from newborn screening are stored in a way that prevents access by unauthorized users.

Alternative option: Parents may choose to have their newborn screened, but to have the blood sample and the results of the testing destroyed twenty four months after testing takes place. Parents may submit the form “Request to dispose of

Newborn Screening test results and/or blood sample” so that the Minnesota Department of Health destroys the results and/or blood sample.

Private entities also offer newborn screening panels. It is up to the parents and/or their medical provider to arrange such screening.

\_\_\_\_\_4. Answer questions to ensure an informed decision. For assistance with any questions, the Minnesota Newborn Screening Program can be contacted at (612) 676-5260.

\_\_\_\_\_5. Review the “Parental Refusal of Newborn Screening Form” with the parent.

\_\_\_\_\_6. Have parent and witness sign the form

\_\_\_\_\_7. Retain the original in the child’s record

\_\_\_\_\_8. Provide copies immediately to the parent, the child’s physician and the  
Minnesota Department of Health  
Newborn Screening Program  
717 Delaware St SE  
PO Box 9441  
Minneapolis MN 55440-9441  
FAX: 612-676-5317

Forms, brochures and additional information are available at:  
<http://www.health.state.mn.us/divs/fh/mcshn/nbs>