

## Primary Care Providers Questions & Answers about NBS

PARENTAL CONCERNS	INFORMATION
Cost of the testing	<p>Most insurers, including Medicaid, cover the cost of newborn screening testing as part of the obstetric diagnostic related group (OB DRG) or for critical access hospitals via a CPT code billing.</p> <p>The laboratory charges the hospital \$45.50 for the newborn screen. The hospital charge for collection and handling of the specimen vary, and are not regulated by the State Newborn Screening Program. The lab does not charge again for requested repeat screens.</p>
The heelstick procedure	<p>The heelstick procedure requires a small puncture to the baby's heel to collect five drops of blood. Hospital staff are trained to follow procedures to minimize the risk of infection. The poke to the baby's heel usually heals quickly and studies show the little pain felt during this time is short lived. Parent may nurse during this time to soothe the baby.</p>
The testing in general	<p>Most people are assured about the value of testing when they understand that this kind of testing:</p> <ul style="list-style-type: none"> <li>• is routinely done</li> <li>• has been done for over 50 years,</li> <li>• is required in all U.S. States, industrialized countries, and some developing countries, and</li> <li>• has saved thousands of newborns from developmental disabilities, long-term physical problems, and infant death.</li> </ul>
Child's insurability if found to have a condition	<p>The Genetic Information Non-Discrimination Act is an important piece of Federal legislation that was passed by Congress and signed by the President in 2008. This Act provides some protections from using genetic information to discriminate against individuals. While this is a legitimate concern, two circumstances that should be considered:</p> <ol style="list-style-type: none"> <li>1) The child is found to have the condition on screening and preventive treatment ensures a healthy life, or;</li> <li>2) The child is found to have the condition only after damage has occurred (because they did not receive the screening results) resulting in developmental disabilities, physical disability, or death.</li> </ol>

	<p>The child with the diagnosis could have problems getting insurance, whether screened or not. It's preferable to get the diagnosis in time to prevent the damaging effects of the condition.</p>												
<p>Ability to care for a child with one of the conditions</p>	<p>There's no question, families face many challenges with some of the conditions. But there are many good resources available in Nebraska, so families don't have to "go it alone."</p>												
<p>Availability of treatment for the disorders</p>	<p>There are specialists who along with many allied health professionals are able to work closely with families to help them provide the care their child needs. Genetic counseling services are also available to help answer additional genetic questions.</p>												
<p>Desire to Refuse testing</p>	<p>The law in Nebraska does not allow parents to sign a "waiver" or "dissent" from the required newborn screening panel. It's not allowed for any reason, religious or otherwise. Courts in Nebraska have heard more than five cases, and in all the judge ruled the child must be screened. An appeal to the Nebraska Supreme Court was heard in 2005. The Nebraska Supreme Court unanimously upheld the requirement that all newborns must be screened. Likewise, a Federal District Court Ruling in 2006 upheld the law.</p>												
<p>Social stigma associated with having an inherited condition</p>	<p>An inherited condition can have major implications for the child's quality of life. However, the quality of life can be improved with early intervention and treatment. Parent to parent support groups and networks are available to help families deal with this.</p>												
<p>Unsure if they understand</p>	<p>The conditions on the newborn screening panel are many and complex. PCPs should provide a basic explanation of newborn screening to parents, and offer to discuss any questions the parents have. This is especially important when literacy skills may be limited.</p> <p>Language barriers may also be an issue. Oral interpreters may be needed if literacy levels are in question, or if the parents don't speak or read any of the available languages of the educational materials. The "Parent's Guide" is available in the following languages:</p> <table style="margin-left: auto; margin-right: auto;"> <tr> <td><i>English</i></td> <td><i>Spanish</i></td> <td><i>Vietnamese</i></td> </tr> <tr> <td><i>Russian</i></td> <td><i>Chinese</i></td> <td><i>French</i></td> </tr> <tr> <td><i>Karen</i></td> <td><i>Sudanese</i></td> <td><i>Anuak</i></td> </tr> <tr> <td><i>Dinka</i></td> <td><i>Nuer</i></td> <td></td> </tr> </table>	<i>English</i>	<i>Spanish</i>	<i>Vietnamese</i>	<i>Russian</i>	<i>Chinese</i>	<i>French</i>	<i>Karen</i>	<i>Sudanese</i>	<i>Anuak</i>	<i>Dinka</i>	<i>Nuer</i>	
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