

For Additional Information

- Visit with your health care provider
- Call the South Dakota Department of Health Newborn Screening Program at 1-800-738-2301
- Visit the South Dakota Department of Health Newborn Screening Program homepage, for links to additional resources:

doh.sd.gov/family/newborn/metabolic/

This pamphlet is available through the South Dakota Department of Health, Newborn Metabolic Screening Program, 600 E. Capitol, Pierre, SD 57501-2536 or by calling (605) 773-3737 or on the Department of Health website: doh.sd.gov/family/newborn/metabolic/



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NEWBORN SCREENING

Saving Babies' Lives



South Dakota Department of Health Newborn Screening Program

What is Newborn Screening?

All newborns in South Dakota are required by law to have a blood test shortly after birth to screen for metabolic and other inherited disorders. The newborn screening helps identify babies who may have one of these disorders, and can alert the baby's doctor to the need for further testing and special care. With early diagnosis and medical treatment, complications from these serious but uncommon disorders may be prevented. This pamphlet was written to help answer your questions about the screening tests.

Why should my baby be screened?

Even if your baby looks healthy, he/she may have one of these disorders. Although these disorders are rare, they are usually serious. Without treatment babies with these disorders could suffer intellectual disabilities, seizures, or even death.

How and when will my baby be screened?

A sample of blood is obtained by pricking the baby's heel. This sample is then placed on special paper which is sent to the designated laboratory for testing. The lab uses this one sample of blood to test for all the required disorders. The sample is usually obtained on the day the baby is discharged from the hospital.



How will I learn of my baby's screening results?

Generally, parents are notified only if retesting or further testing is needed. You can ask about the results when you take your baby in for a regular check-up. If your baby's doctor asks you to bring your baby in for retesting or further testing, do so as soon as possible. The results of the tests are returned to the hospital where your baby was born.

What if my baby needs to be re-tested?

There are 3 main reasons why a repeat screening test may be needed:

- (1) There was a problem with the sample,
- (2) The test was done prior to 24 hours of age, or
- (3) The test result was abnormal. Generally, if the results of the repeat screening test are also abnormal, the doctor will discuss the need for further treatment or testing. It is important that your hospital and doctor have your correct address and phone number to contact you. If your baby needs to be retested, get it done as soon as possible.

What happens to my baby's blood sample after the lab tests it?

The newborn screening laboratory will destroy your baby's blood sample once it is no longer needed for testing. It will not be used for any purpose other than newborn screening. If you have questions about how your baby's blood sample is handled, call the South Dakota Newborn Screening Program at (605) 773-3361.

Disorder	What is it?	What happens if not treated?	Treatment
Expanded Screening <ul style="list-style-type: none"> • Amino Acid disorders (AA) disorders (includes Homocystinuria, PKU testing & Maple Syrup Urine Disease) 	These disorders are conditions that limit the body's ability to break down certain proteins.	Babies become very sick, become intellectually disabled or may die.	Special diet.
<ul style="list-style-type: none"> • Fatty acid oxidation (FAO) disorders (includes MCAD- medium chain acyl CoA dehydrogenase deficiency) 	These disorders affect the body's ability to make energy and to use the body's stored energy.	Can cause seizures, coma and even death.	Making sure infants and children are eating and drinking regularly, especially when they are ill.
<ul style="list-style-type: none"> • Organic Acid (OA) disorders 	These disorders lead to high levels of acids in blood and urine.	Can cause seizures, intellectual disability and death.	Special diet and medicine.
Biotinidase Deficiency	The baby is unable to use the vitamin, biotin.	Babies grow very slowly and can become intellectually disabled.	Daily biotin supplement.
Congenital Adrenal Hyperplasia	The body cannot make enough of certain types of hormones.	Affects growth and development. The body has trouble maintaining a balance of salt causing vomiting, dehydration, and heart problems. If left untreated, death.	Special medicine.
Congenital Hypothyroidism	The thyroid gland doesn't produce enough of the hormone thyroxine.	Babies do not grow and develop properly and become intellectually disabled.	Medication – thyroxine.
Cystic Fibrosis (CF)	Causes mucus to build up in the baby's lungs and intestines.	Causes problems with breathing and digesting food.	Regular medical care and a good diet.
Galactosemia	The body cannot use a certain sugar (galactose) found in dairy products.	Babies become very sick, have liver and eye damage, become intellectually disabled or even die.	Special diet.
Hemoglobinopathies (Sickle Cell Anemia)	Red blood cells tend to change from the normal round shape to an abnormal sickle shape, which may cause blockage of blood flow.	Babies with sickle cell disease can get very sick and even die from common infections.	Antibiotic treatment may lessen problems.
Severe Combined Immunodeficiency (SCID)	Affects the function of infection-fighting cells causing very little or no immune system.	It can be difficult or impossible to fight infections. If left untreated, it almost always causes death within the first year of life.	Bone marrow transplant.