Virginia Newborn Screening Services

What are Virginia's Newborn Screening Services (VNSS)? The Virginia Department of Health (VDH) and the Division of Consolidated Laboratory Services (DCLS) work together to identify babies that have rare, but serious disorders though dried blood spot screening. These disorders can be treated and problems can be prevented if they are found early in life. Babies with these disorders look healthy at birth, and screening helps to identify them before the disorder causes the baby to become sick. The baby's doctor is alerted to any potential problem identified by the test results. Repeat testing can be done on infants up to 6 months of age. Virginia currently screens for 28 disorders.

How is my baby tested? Your baby's heel will be pricked to get a few drops of blood. The blood will be placed on special paper and allowed to dry. The paper will then be sent to DCLS. The lab only needs a tiny bit of blood to perform all the testing described in this pamphlet.

When is the best time to test my baby? As per Virginia Code 12VAC5-71, Newborn dried-blood-spot specimen collection shall occur after 24 hours of age or immediately before the newborn's discharge from the hospital, whichever comes first. If the initial newborn dried-blood-spot specimen is collected before 24 hours of age, a repeat specimen shall be collected at the time of discharge from the hospital or no later than 14 days of age, regardless of earlier test results. For every live birth in the Commonwealth, the physician or midwife in charge of the infant's care after delivery shall ensure the initial collection and submission of a newborn dried-blood-spot screening specimen for testing.

Is my permission needed for testing? Newborn screening is so important to the health of babies that it is required by state law. Parents may refuse screening only if it conflicts with religious practices. A refusal form must be signed and it is placed with the baby's medical record.

How much will this test cost? DCLS charges the hospital a fee of $78.00 for doing the screening tests on your baby's blood sample. In addition, the doctor, clinic, or hospital may charge a small fee to do the heel prick.

What part can I play to make sure all of this comes together? It is very important that your doctor or clinic can contact you. Do not leave the hospital without leaving an address and phone number where you can be reached. If you do not have a phone, leave a number where someone can contact you without delay.

What if my baby's test indicates a problem? **These are screening tests only. They do not diagnose disorders**. If your baby's screening indicates a possible problem, your doctor or healthcare provider will notify you and additional testing may be required. Sometimes screening may indicate a potential problem, but further testing shows no problem to be found. However, if a diagnosis is confirmed by testing, your baby will need follow up treatment.

Can these disorders be cured? There are no cures for these disorders. However, with early diagnosis and proper treatment they can be managed effectively and sometimes symptoms can be prevented. The treatment is usually a special diet or medication.

How does a baby get these disorders? For most of these disorders, a baby inherits a changed gene from both parents. Each parent has one functioning gene and one changed gene. Parents usually show no sign or symptom of the disorder.

Will my other children have the disorder? This depends on your child's diagnosis. A trained professional or Genetic Counselor can study your family's history and explain the chance of the disorder happening again. Your doctor or clinic can help you locate a genetic counselor and other genetic services that may assist your family.

How will I be informed of the results? Your hospital, doctor, or clinic will be sent a copy of all test results from the lab. You are encouraged to ask your baby's healthcare provider about the results during an office visit. ***It is very important that the Doctor information you give the nursery staff is correct. This will make it possible to contact your doctor if the test indicates a problem***

Why would my baby need to be retested? Sometimes a baby will need to have another screening sample collected. This does not mean there is anything wrong with your baby. Possible reasons for a repeat test are:

- The 1st sample was improperly collected or not received in a timely fashion.
- The first test may indicate a possible problem
- The baby had a blood transfusion prior to collection of the first sample.

For more information about the following disorders, please visit: www.vahealth.org/genetics

Medium Chain Acyl -CoA Dehydrogenase Deficiency (MCAD)

Long Chain Hydroxyacy-CoA Dehyrogenase Deficiency (LCHADD)

Tri-functional Protein Deficiency (TFP Deficiency)

Very Long Chain Acyl-CoA Dehydrogenase Deficiency (VLCADD)

Carnitine Uptake Deficiency (CUD)

Isovaleric Acidemia (IVA)

Glutaric Acidemia Type I (GA-1)

3-Hydroxy-3Methylglutaryl-COA Lyase Deficiency (HMG)

Multiple CoA Carboxylase Deficiency (MCD)

Methylmalonyl-CoA Mutase Deficiency (MUT)

Methylmalonyl Adenosyl-Cobalamine Synthesis Defects (Cbl A& B)

Methylcrotonyl-CoA Carboxylase Deficiency (3MCC)

Propionic Acidemia (PROP)

Beta-Ketothiolase Deficiency (BKT)

Argininosuccinic Aciduria (ASA)

Citrullinemia (CIT)

Galactosemia (GALT)

Phenylketonuria (PKU)

Tyrosinemia I (TYR I)

Homocystinuria (HCU)

Hypothyroidism

Biotinidase Deficiency (BIOT)

Hemoglobinopathies

Maple Syrup Urine Disease (MSUD)

Cystic Fibrosis (CF)

Congenital Adrenal Hyperplasia (CAH)

Severe Combined Immunodeficiency (SCID)