10 Things Parents Want To Know About Newborn Screening
From Their Baby’s Health Professional

1. The Texas Newborn Screening Program checks all newborn babies for a number of rare disorders. The screening tests are very important for your baby’s health.

2. Babies with these disorders may look healthy at birth. Many disorders can’t be seen.

3. Serious problems, such as an intellectual/developmental disability, illness, or death, may be prevented if we find the disorders right away.

4. Newborns are first tested 1 to 2 days after birth before they leave the hospital and again at 7 to 14 days of age in their doctor’s office or clinic.

5. To do the test, a health professional will take a few drops of blood from your baby’s heel.

6. Your baby’s health professional or the hospital will get a copy of the test results. Call your baby’s health professional if you would like to talk about the results.

7. Some babies may need more tests. You will be notified if your baby needs more tests. It is very important for your baby to get these tests quickly.

8. The blood spot cards are stored for up to 2 years, and may be used to ensure laboratory tests, equipment and supplies are working right, to develop new tests, and for Department of State Health Services studies of diseases that affect public health.

9. If you give your OK, the blood spot cards will be stored for up to 25 years, and may be used for public health research outside of the Department of State Health Services. You, the parent/guardian, decide what the lab does with your baby’s blood spots after testing by completing and sending in a decision form. The decision form will be given to you when the blood spots are collected. Your baby’s information stays private and secure no matter your decision.

10. For more information, talk to your baby’s health care provider. If you have more questions about newborn screening, call the Texas Department of State Health Services - Newborn Screening Program at 1-800-252-8023 ext. 3957. If you have more questions about bloodspot card records, call 1-888-963-7111 ext. 7333.
Homocystinuria (HCY) HCY is caused by an enzyme deficiency that blocks the metabolism of an amino acid that can lead to intellectual/developmental disabilities, osteoporosis, and other problems if left undetected and untreated. The incidence is approximately 1 in 350,000 U.S. newborns. Treatment may involve dietary restrictions and supplemental medicines.

Maple Syrup Urine Disease (MSUD) MSUD is a defect in the way that the body metabolizes certain amino acids and is present in about 1 in 200,000 U.S. newborns. Early detection and treatment with dietary restrictions can prevent death and severe intellectual/developmental disabilities. There is an increased risk in Mennonites.

Medium Chain Acyl-CoA Dehydrogenase (MCAD) Deficiency The most common disorder in the way the body metabolizes fatty acids is called MCAD deficiency. Undetected, it can cause sudden death. Treatment is simple and includes ensuring regular food intake. The incidence from newborn screening is not yet known, but is thought to be approximately 1 in 15,000 newborns.

Other Fatty Acid Oxidation (FAO) Disorders Besides MCAD deficiency, other FAO disorders may be detected through newborn screening. They are usually described in categories based on the length of the fatty acid involved. Undetected and untreated they can cause seizures, coma, and even death. The incidences of various FAO disorders are not known since it is only recently that early detection through newborn screening has occurred.

Organic Acid (OA) Disorders Organic acidemias are a group of metabolic disorders that lead to buildup of organic acids in the blood and urine and may be detected in newborn screening through analysis of acylcarnitine profiles. Restricting protein in the diet and supplementation with vitamins and/or carnitine can diminish symptoms. Because newborn screening for these disorders is relatively new, the degree of occurrence in newborns is not yet known.

Phenylketonuria (PKU) An enzyme defect that prevents metabolism of phenylalanine, an amino acid essential to brain development, is known as PKU. It occurs in approximately 1 in every 15,000 newborns. Undetected and untreated with a special diet, PKU leads to irreversible intellectual/developmental disabilities. Persons of European descent are at increased risk.