## Texas Department of State Health Services

## Newborn Screening Program Frequently Asked Questions

**Q. What is the newborn screening program?**

A. The Texas Department of State Health Services (DSHS) Newborn Screening Program consists of testing, follow-up and clinical care coordination. All babies born in Texas are required to have two rounds of screening tests for certain inheritable and other disorders. The Newborn Screening Program identifies those infants who have an abnormal screen at birth or shortly after birth. An abnormal laboratory result triggers follow-up and case management to ensure that the baby receives confirmatory testing and treatment, if needed. Early treatment can prevent serious complications such as growth problems, developmental delays, deafness or blindness, mental retardation, seizures or even early death.

**Q. What is the history of newborn screening in Texas?**

A. A pilot for phenylketonuria (PKU) screening was implemented in Texas in 1963. PKU testing was mandated by the 59th Legislature in 1965. Screenings for additional disorders were added with galactosemia in 1978, congenital hypothyroidism in 1980, sickle cell disease in 1983 and congenital adrenal hyperplasia (CAH) in 1989.

**Q. How are newborns tested?**

A. A tiny amount of blood is taken from the baby's heel 24 hours to 48 hours after birth or before leaving the hospital. A second sample is taken one to two weeks later, usually at baby's first check-up. The sample is put on a piece of absorbent paper, dried and sent to the DSHS laboratory in Austin for screening tests.

**Q. What conditions does the newborn screening program cover?**

A. **Six amino acid disorders:** argininosuccinic academia (ASA), citrullinemia (CIT), homocystinuria (HCY), maple syrup urine disease (MSUD), phenylketonuria (PKU) and tyrosinemia type I (TYR-I);
**Two endocrine disorders:** congenital adrenal hyperplasia (CAH) and congenital hypothyroidism (CH);
**Five fatty acid oxidation disorders:** medium chain acyl-coenzyme A dehydrogenase deficiency(MCAD), carnitine uptake defect (CUD), long-chain L-3- hydroxyacyl-coenzyme A dehydrogenase deficiency (LCHAD), trifunctional protein deficiency (TFP) and very long-chain acyl-coenzyme A dehydrogenase deficiency (VLCAD);
**Three hemoglobinopathies:** sickle cell anemia (Hb S/S), sickle beta thalassemia (Hb S/A), and sickle-hemoglobin C disease (Hb S/C);
**Nine organic acid disorders:** 3-methylcrotonyl-coenzyme A carboxylase deficiency (3-MCC), beta-ketothiolase deficiency (BKT), glutaric acidemia type I (GA-I), 3-hydroxy 3-methylglutaric aciduria (HMG), isovaleric academia (IVA), methylmalonic acidemia (Cbl A,B form), methylmalonic acidemia (MUT), multiple carboxylase deficiency (MCD) and propionic acidemia (PROP); and
**Two other disorders:** biotinidase deficiency (BIOT) and galactosemia (GALT).

**Q. Why are two screens required in Texas?**

A. Standard practice is to take the first sample early, during the hospital stay, to detect disorders at the earliest possible chance. In some cases, the first sample may not identify all abnormal screens, and a disorder may be detected only on the second screen.

**Q. Why is newborn screening important?**

A. Most children born with these problems are from healthy families and appear healthy at birth. Parents who have already had healthy children do not expect any problems with birth defects. Because every baby is tested soon after birth, any child who may have a disorder is identified early and can get immediate care.

**Q. Who does the screening?**

A. The health care provider takes the blood sample. The DSHS public health laboratory in Austin does the screening tests.

**Q. What happens if a disorder is found during screening?**

A. If screening tests are positive for any disorder, DSHS case management follow-up staff contacts the health care provider to quickly relay these critical results and then works with the health care provider and parents to ensure the infants get recommended follow-up screens or confirmatory testing.

**Q. What are the statistics for screening in Texas?**

A. Estimated 2007 Statistics indicate there were approximately 400,000 births in Texas. The DSHS Laboratory received approximately 800,000 specimens collected and Case Management provided follow-up on approximately 15,000 abnormal screens. There were approximately 600 diagnosed core disorders and more than 300 cases of variant or other disorders.

**Q. Can infants with any of these disorders be cured?**

A. There is no cure for these conditions. Early treatment may prevent or control the serious effects.

**Q. Can parents opt out of having their newborn screened?**

A. Yes. A parent can refuse the screen for religious reasons.

**Q. Is the only reason a parent can refuse for religious reasons?**

A. The statute’s only reference to allowing the parent, guardian or managing conservator the right to object to screening is if it conflicts with their religious tenets or practices.

**Q. Who pays for the screening?**

A. The health care provider or facility sending the specimen to the laboratory buys the specimen collection kit for private pay patients. How these patients are billed is determined by the commercial insurance carrier.