TEXAS
Newborn Screening Program NEWS
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# WHAT TO TELL PARENT'S WHEN THEIR BABY'S SCREEN IS ABNORMAL

## What Is A Newborn Screen?

The Texas Newborn Screening Program tests for five disorders which, if not treated very early in life, can cause severe mental retardation, illness or death. The two inborn errors of metabolism, phenylketonuria (PKU) and galactosemia, are treated by diet; congenital hypothyroidism and congenital adrenal hyperplasia (CAH), are treated by medication; and sickle cell disease complications may be prevented through a program of medical supervision and prophylactic antibiotics administered at an early age.

## How Was My Baby Tested?

All the blood tests are done on tiny samples of blood taken from your baby's heel about two days after birth. The Texas Department of Health Laboratory in Austin tests the sample. Some tests may not give accurate results if the sample is taken too soon after birth. It is required that a repeat specimen be taken about one to two weeks later.

## But We've Never Had Any Birth Defects In Our Family...

Most of the children born with these problems are from healthy families. Parents who have already had healthy children do not expect any problems with birth defects. By testing every baby after birth, we can be sure to find each infant who has one of the screened disorders and start them on early treatment. As this is a screen, it identifies a group of babies who need further evaluation. Most of these babies will NOT have one of these conditions.

## I Received A Letter From The "Follow-Up Program." What Is That?

An active follow-up system is maintained by the Texas Department of Health-Newborn Screening Program on all abnormal reports. Health care providers are contacted by mail or telephone or fax with instructions for further testing. Public health nurses and social workers are often utilized to help locate families and assist with follow-up procedures. A registry is maintained on all newborns diagnosed with screened disorders. Children diagnosed through the program are followed at regular intervals to monitor health status.

## If My Baby Has One Of These Disorders, Can It Be Cured?

You can't cure these conditions, just as you can't permanently change eye color or height. However, early treatment may prevent or control the serious effects of these disorders. Pediatric endocrinology, hematology and metabolic consultants are available at several centers throughout the state to assist the private physician with diagnosis and treatment of children identified through the program.

For free literature on the Texas Newborn Screening Program, please call 1-800-422-2956 and ask for extension 3204, or visit our publications web site at: http://www.tdh.state.tx.us/newborn/pubs.htm

# NEWBORN SCREENING PROGRAM RULES

TEXAS ADMINISTRATIVE CODE
TITLE 25 / HEALTH SERVICES

*Frequently Asked Questions*

Q. **Who has the responsibility of ensuring the newborn screens are collected?**
A. §37.55. Responsibilities of Persons Attending a Newborn.

(a) The physician or non-physician attending the newborn has the primary responsibility for causing the screening tests to be performed according to these sections and that a satisfactory blood specimen is submitted to the department on a properly completed filter paper collection form obtained from the department.

Q. **When should the screens be collected?**
A. §37.56. Blood Specimen Collection for Required Screening Test.

(a) Optimally, the blood specimen is to be obtained after 36 hours of age and 24 hours after the first protein feeding. If the newborn is discharged from the hospital or birthing center before the above criteria are met, the specimen must be obtained immediately prior to discharge. A second specimen is to be collected between one and two weeks of age.

(b) Premature or sick newborns may have the initial screen as late as seven days of age. The second screen on premature or sick newborns is to be done at hospital discharge, one month of age, when the newborn attains a weight of 2500 grams, or whenever requested to do so by the program, whichever comes first.

(c) Newborns delivered outside hospitals or birthing centers (e.g. home deliveries), must be screened within the first 72 hours of life. The second screen must be done between one and two weeks of age.

Q. **Are any newborns exempted from the newborn screen?**
A. §37.54. Exemption from Screening. A newborn may not be screened if the parent, managing conservator or guardian objects to the screening tests because the screening tests conflict with the religious tenets or practices of the parents, managing conservators or guardians.

Q. **What conditions are in the screening panel?**
A. §37.53. Conditions for which Newborn Screening Tests are Required. Except as permitted in §37.54 of this title (relating to Exemption From Screening), all newborns delivered in Texas shall be subjected to two screening tests for the following conditions:

(1) phenylketonuria;
(2) galactosemia;
(3) sickling hemoglobinopathies, including sickle cell disease;
(4) congenital adrenal hyperplasia; and
(5) hypothyroidism.

Free copies of the Texas Newborn Screening Practitioner's Guide are available by calling 1-800-422-2956, ask for extension 3204 or visit our web site: http://www.tdh.state.tx.us/newborn/newborn.htm and select Practitioner's Guide.


**Texas Department of Health**
**Newborn Screening Program**

**Margaret Drummond-Borg, M.D., Director**
**Genetic Screening and Case Management**

**Susan U. Neill, PhD., M.B.A., Director**
**Biochemistry and Genetics Division**
**Bureau of Laboratories**

**Lynette Borgfeld, MT (ASCP)**
**Branch Supervisor**
**Newborn Screening Laboratory**

**Daisy Johnson, R.N., B.S.N.**
**Congenital Hypothyroidism**

**Carolyn Scruggs, R.N.**
**PKU, CAH, Galactosemia**

**Nkechi Eke, R.N., B.S.N.**
**Hemoglobinopathy**

**Michele M. Goddard, MPA**
**Editor**